

**The Development of an Online Neonatal Intensive Care Unit Family Education  
Guide**

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## **Abstract**

**Background:** British Columbia's Fraser Health Authority (FHA) neonatal intensive care units (NICUs) value family centered care (FCC). Nevertheless, there is limited evidence that FCC is actually incorporated into practice, as well as some concern that FHA NICU education is inaccessible, inconsistent, or disorganized.

**Purpose:** The mission of this project is to support the principles of FCC throughout the development of an FHA online NICU family education guide by reflecting upon the needs of families throughout their NICU journey.

**Methods:** A needs assessment was initially completed and included literature reviews, consultations, and an environmental scan. This data informed development of an online NICU family education guide which plots current education materials along key stages of the NICU journey: prenatal, admission, early days, growing and developing, discharge and at home. For the purposes of this practicum, only the prenatal stage was fully developed and will serve as a template for other stages following a formative evaluation. A pamphlet and revised FHA Neonatal Checkpoint will also be developed to augment teaching by health care professionals. Implementation and evaluation plans were adapted from the Center for Disease Control Framework for Program Evaluation in Public Health.

**Results:** The needs assessment validates and directs the development, implementation, and evaluation of the online guide illustrating an FCC approach. The online guide centralizes and organizes education by selecting education topics that relate to each stage of the NICU journey. This family-directed design enables families' access to consistent and reliable information and offers them an opportunity to learn at their own pace.

**Conclusion:** The process of creating, implementing, and evaluating an online family education program for FHA NICUs elucidates the intricacies and the advantages of integrating FCC into NICU practice.

*Keywords:* neonatal intensive care (NICU), family, family centered care (FCC), parenting, education, online

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## **Introduction**

The neonatal intensive care units (NICUs) in British Columbia's Fraser Health Authority (FHA) value family centered care (FCC). FCC is an approach that is centred upon a belief that outcomes improve when families are considered partners and included in all aspects of care (Gooding et al., 2011). Principles of FCC include ensuring respect and dignity, information sharing, participation, and collaboration (Griffin, 2006). Providing families in the NICU with education supports FCC. In addition, the evidence suggests that families, infants, and health care organizations benefit from NICU family education. Indeed, it has the potential to decrease length of stay, improve infant outcomes, increase family satisfaction, confidence, and visitation, as well as reduce families' stress and facilitate collaboration among health care professionals (Brett, Staniszewska, Newburn, Jones, & Taylor, 2011; Gonya & Nelin, 2012; Leonard & Mayers, 2008; Smith, Deai, Sira, & Engelke, 2014). Although the benefits of NICU family education and its relevance to FCC are apparent the evidence suggests that incorporating FCC into practice is vague and sporadic (Gooding et al., 2011; Mikkelsen & Frederiksen, 2011). As a result, the mission of this project is to support the principles of FCC throughout the planning of an FHA online NICU family education guide by reflecting upon the needs of families throughout their NICU journey.

The FHA encompasses a large area within the lower mainland of British Columbia; there are five NICUs within this entire region. The FHA NICUs total 74 beds but each unit has varying acuity, census, layout, and allied health support. Despite these differences every member of the FHA NICU health care team is responsible for educating families and it is valuable to have resources, such as an online family education guide, to

augment this teaching. A needs assessment was conducted to inform the development of this guide as well as support the principles of FCC. Overall, the needs assessment consisted of gathering evidence to gain a greater understanding of NICU families' needs, identify features of effective education programs, and compile current FHA education resources.

The results of the needs assessment validated and facilitated the program's development process as well as the guide's content and format. First, there is pervasive evidence within the literature that employing an evidence based practice (EBP), FCC approach during program development, implementation, and evaluation positively contribute to program effectiveness (Borimnejad, Mehrnoosh, Fatemi, & Haghani, 2013; Melnyk, Bullock, Jacobson, Kelly, & Baba, 2010; Melnyk et al., 2006; Morey & Gregory, 2012). Second, awareness of NICU families' experiences elucidated the need to ensure that family education is accessible, consistent, organized, and family directed (Arockiasamy et al., 2008; Burnham, Feeley, & Sherrand, 2013; Cleveland, 2008; Dunn, Reilly, Johnston, Hoopes, & Abraham, 2006; Goldstein, 2013; Heinemann, Hellstrom-Westas, & Hedberg-Nyqvist, 2013; Hollywood & Hollywood, 2010; Hurst, 2006; Melnyk et al., 2006; Obeisat & Hweidi, 2014; Pepper, Rempel, Austin, Ceci, & Hendson, 2012; Schlittenhart, Smart, Miller, & Severtson, 2011; Smith, SteelFisher, Salhi, & Shen, 2012; Staniszweska et al., 2012; Willis, 2008). Finally, the content and format of the guide was directed by families' unique and changing responses and coping strategies during their infant's NICU admission, which is often related to a journey (Aagaard & Hall, 2008; De Rouck & Leys, 2009; Grosik, Synder, Cleary, Breckenridge, & Tidwell, 2013; Lunkqvist, Wetas, & Hallstrom, 2007; Redshaw & Hamilton, 2010).



The needs assessment results verified the benefits of education for families and offered further advantages. A significant benefit of education is the fact that it helps families cope and facilitates attainment of their parental role (Heinemann et al., 2013; Lunkqvist et al., 2007; Smith et al., 2012). In addition, the needs assessment offered details about the ways in which families acquire knowledge (Cleveland, 2008; Heinemann et al., 2013; Hollywood & Hollywood, 2010; Obeisat & Hweidi, 2014; Pepper et al., 2012). Lastly, it is apparent that the needs assessment data supports the principles of FCC by facilitating a greater understanding of families' needs while also acquiring insight into their perspectives in order to offer reliable and appropriate education that aims to help families become more involved.

The following report provides details on the development, implementation, and evaluation of an online NICU family education guide. The first section presents the objectives and methodology, which are key steps in the planning process. The second section describes the development phase. This section presents a summary of the needs assessment as well as a comprehensive description of and rationale for the guide. The third section discusses the remaining steps to be completed in the developmental process followed by the implementation and evaluation plans. The final section focuses on how this project demonstrates the Canadian Nurses Association's (CNA) four Advanced Nursing Practice (ANP) competencies. Overall, this project highlights the complexities but also the benefits of integrating FCC into NICU practice.

### **Objectives**

The overall mission of this practicum was to develop an online family education guide that organizes the FHA NICU family education, meets the needs of NICU families

throughout their NICU journey, and supports the principles of family centered care. The specific outcome objectives were:

1. Perform a needs assessment to gain a greater understanding of the needs of NICU families and to identify features that contribute to a successful NICU family education program.
2. Develop an online FHA NICU family education guide that incorporates the principles of FCC and reflects on the needs assessment results to facilitate the organization and delivery of FHA NICU family education.
3. Develop tools for NICU health care professionals (HCPs) to augment their teaching. This was accomplished by developing a pamphlet for NICU HCPs that highlights the content of the online NICU family education guide, and revising the neonatal checkpoint to ensure it is reflective of the current available resources.
4. Develop an implementation plan for the application of the online NICU family education guide based on the Center for Disease Control Framework for Program Evaluation in Public Health.
5. Demonstrate Canadian Nurses Association's four Advanced Nursing Practice competencies: clinical, research, leadership, and consultation and collaboration.

### **Methods**

Several methods were employed to achieve the target outcome objectives for this practicum. The primary method involved completing a needs assessment. A comprehensive description of each component of the needs assessment is presented in

Appendix A while a brief summary is presented in this report. The needs assessment consisted of conducting two literature reviews, leading consultations with key stakeholders, and completing an environment scan. Next, the FHA NICU family education shared work team was founded and education materials were organized. Then, the design and content of the online guide was established and is illustrated in Appendix B. At this point, a template was created, exhibited in Appendix C, in order to perform a formative evaluation. Following this evaluation, the remaining sections of the guide will be developed. Tools will also be created to assist HCPs and are presented in Appendix D and E. Finally, an implementation and evaluation plan has been outlined that will direct the launch and appraisal of the guide (see Appendix G).

### **Summary of the Literature Reviews**

Two electronic literature reviews represented the main source of secondary data collection. The literature reviews focused on the informational needs and experiences of NICU families and NICU family education programs. A systematic search for relevant English language articles published since 2005 was completed in Medline, EMBASE and CINAHL, using a combination of search words. Titles, abstracts and content of articles were screened to determine their relevancy for addressing the research questions.

The literature searches resulted in a combination of qualitative and quantitative studies. Critique of qualitative research was guided by the critical appraisal skills programme (CASP) (Critical Appraisal Skills Programme, 2013) whereas critique of quantitative research was guided by the Public Health Agency of Canada's Infection Prevention and Control Guidelines: Critical Appraisal Tool Kit (Public Health Agency of

Canada [PHAC], 2014). A comprehensive overview of the critical appraisal rating of each article included in the reviews is located in summary tables A1 – A4 in Appendix A.

### **NICU Family Needs and Experiences**

The research question guiding this review was: What are the experiences of parents with infants admitted to the NICU. Following in-depth analysis of the twenty articles selected for review, six themes emerged: response, support, knowledge acquisition, involvement, individualized needs, and NICU journey.

A major theme emerging from the reviewed studies is that the needs of families are diverse due to the range of emotions experienced and varied coping strategies that are employed to address them. In addition, multiple factors that may trigger positive and negative experiences have been identified, such as the NICU environment or perception of available support. Several strategies for promoting effective coping, such as delivery of consistent, reliable, and repeated information or helping families become involved in their infant's care, are also presented in the literature. The success of any one strategy or combination of any method, however, is complicated by the fact that families have unique and changing needs throughout their NICU journey. A common theme noted in the literature is that individualizing care provides families with optimal support during such a challenging and personalized experience.

### **NICU Family Education Programs**

The research question guiding this review was: What are the key components of a successful NICU parent education program? Following in-depth analysis of the thirteen articles selected for critical appraisal, four themes emerged: planning and EBP, FCC and

program effectiveness, individualized and family directed approach, and formats and content.

There is extensive evidence within the literature that indicates the effectiveness of employing EBP and incorporating FCC principles during program development, implementation, and evaluation. For example, use of EBP and a FCC approach includes conducting a comprehensive needs assessment, developing program goals that relate to the principles of FCC, or ensuring involvement of family members. In addition, the evidence suggests that effective programs use a variety of delivery methods and address a multitude of topics. As a result, it is beneficial to offer a structured, family directed format. For example, it is important to identify and organize the informational needs of families throughout the NICU journey and present requisite information to them using an engaging, diverse, adaptive, and family directed design.

### **Summary of the Consultations**

An important source of primary data collection was informally consulting with the FHA NICU healthcare team, FHA NICU families, and a FHA patient education consultant. As these consultations did not answer specific research questions, ethics approval was not necessary. The primary purposes of the consultations focussed on gaining a greater understanding of the experiences of FHA families and establishing connections with key stakeholders. Detailed descriptions of the setting, participants, methods, data collection, management, analysis, and results of these consultations are presented in Appendix A. A brief summary of the consultations will be presented in this report. Overall, the knowledge gained from all of these consultations aimed to ensure a

greater understanding of the target population's specific needs. Suitably, the results of the literature reviews and consultations complemented each other.

### **FHA NICU Health Care Team**

The FHA NICU health care team is familiar with the NICU environment and possesses a great deal of experience working with and teaching families. The team members that agreed to be consulted included registered nurses, neonatal therapists (physiotherapists, occupational therapists, speech language pathologists), a discharge planning nurse, a clinical nurse educator, and a clinical nurse specialist. The consultation of this multi-disciplinary team was guided by the question: What are the informational needs of FHA families?

The NICU team's responses focused on families' knowledge acquisition. They provided insight about who asks for information, where, why, when, and how they ask for information, and what information they typically request. In particular, the team noted that families not only request validation for the care being provided but their questions tend to be future-orientated, repetitive, personalized, and changeable over time. While families pose many questions, they also seek support from the team. Numerous approaches that were thought to have positive outcomes were identified by the team. For example, reassurances during hands on experiences were thought to build the confidence of families, whereas conversing with members of the team was thought to facilitate the assumption of their parental roles. It is apparent that ultimately families aspire to learn; this desire helps families gain a greater understanding of their experience.

**FHA NICU family education shared work team.** During the initial consultation with the NICU Health care team, the FHA NICU family education shared work team

(SWT) was created. The members of this multidisciplinary SWT, therefore, demonstrated enthusiasm and motivation to offer further contributions to this project. FHA NICU managers sponsored the SWT but I was assigned the responsibility of guiding their activities. As the SWT's leader I planned, directed, and documented the monthly meetings as well as disseminated the meeting's minutes.

The SWT provided feedback on the mission, goals, and objectives. Although my role was to create the discussion guide for the consultations with NICU families, members of the SWT were also involved in these discussions. Also, it was my role to itemize all available education while the SWT helped me plot these materials along the NICU journey. As team leader, I was responsible for conducting the needs assessment and generating a report of the results. Brainstorming sessions were held with the SWT to identify ideas for the format and content of the guide which helped me to create an outline and initial draft of the guide. The SWT provided valuable feedback for both the outline and the draft and will continue to meet monthly and offer further feedback on the complete guide once I finalize it. Finally, the SWT will play an active role in the implementation and evaluation plan.

The SWT also helped to ensure the project was on target and the guide incorporated a FCC approach. Upon review, the guide demonstrates a FCC approach as the needs assessment data supports the two FCC principles of respect and dignity and collaboration. Once implemented, it is expected that the two remaining principles, information sharing and participation will be supported. The guide, therefore, ensures an awareness and appreciation for families' experiences and includes families in all aspects of program development.

### **FHA NICU Families**

English speaking families within three FHA NICUs, with varying acuity, layout, and census, were approached to determine the needs of the target population. This consultation was guided by the question: Is FHA family education effective?

Overall, families found the education they received to be helpful, easy to understand, and pertinent. While this was encouraging, additional education topics were also identified. Families also appeared to be future orientated and identified a need for emotional and administrative support. In addition, families acknowledged a preference for more than one format, such as written material, classes, videos, and photos.

### **FHA Patient Education Consultant**

The FHA patient education department offers guidance, conducts ongoing evaluations and catalogues FHA patient education. Establishing a connection with this department at the beginning of this project was beneficial and aimed to ensure the online guide offers appropriate content and an engaging format. The guiding question for this discussion was: How can the Fraser Health patient education department assist with this project?

Throughout the discussion it was apparent that the consultant possessed a unique set of skills and contacts that would prove to be beneficial to this project. For example, the consultant identified that the project was on target and also offered an explanation of the department's roles and responsibilities. Above all, the patient education consultant also verified that all of the available resources within FHA had been retrieved.



### **Summary of the Environmental Scan**

The other source of primary data was the completion of an environmental scan. This entailed gathering and organizing current education available within FHA. There are currently two main sources of family education within FHA: patient education catalogue and HealthLink BC. A list of the retrieved resources is presented in tables G1-G3 in Appendix A.

Upon review of the current resources available, both strengths and limitations were identified. The major strength is an abundance of resources in a variety of languages. For example, there are 54 topics on the patient education catalogue and 79 topics on HealthLink BC that relate to the NICU. The main limitations are that the education materials appear to be disorganized, inconsistent, unavailable, and unit specific. For example, to access NICU related education in the patient education catalogue, families or HCPs are required to first find the catalogue and then search for a specific topic.

Overall, it is encouraging that the relevant education is available but it could prove to be more effective if it is available in a centralized location and organized into topics that relate to each step of the NICU journey. This would, in turn, help ensure that education is consistent, accessible, and organized for NICU families and HCPs. The environmental scan, therefore, validates the development of a FHA online NICU family education guide.

### **Summary of the FHA Online NICU Family Education Guide**

The comprehensive needs assessment augmented the FHA NICU family education SWT's awareness of the needs and experiences of families and elucidated the

areas requiring improvement. The influence of the needs assessment is especially exemplified in the selected format, organization, and content of the guide. In brief, an online guide that organizes current FHA NICU family education along the six stages of the NICU journey was created.

A variety of possible formats was discussed but the creation of an online guide was deemed the best choice. Indeed, an online format offers many benefits that relate to the needs of families. To begin with, the online format centralizes all the education that is available; this ensures families have access to consistent and reliable education. The literature, consultations, and environmental scan identified that these are important features for a NICU education program (Cleveland, 2008; Heinemann et al., 2013; Hollywood & Hollywood, 2010; Obeisat & Hweidi, 2014; Pepper et al., 2012). For example, although all of the current written information available to families is online it was ascertained that it was not always consistent or easy to access.

The online format will also facilitate links to various reliable resources and topics such as growth and development charts or immunization reminder applications for mobile devices. Links will also offer families the opportunity to learn more details about specific topics as they will be able to simply click on key words for more in depth information. The online format also facilitates links to topics that apply to more than one stage. For example, expressing breastmilk relates to the prenatal, admission, and early days stage but a comprehensive discussion on this topic will only occur in the admission stage. Links, however, to this discussion will exist on the prenatal and early days stage.

Another advantage to the online format is that it offers a family directed approach. The needs assessment identified that this is an important feature as families' learning and

support needs are unique and constantly changing (Aagaard & Hall, 2008; De Rouck & Leys, 2009; Grosik et al., 2013; Lunkqvist et al., 2007; Redshaw & Hamilton, 2010). A family directed approach allows families to pace their learning while giving them the opportunity to review the information at any time. Similarly, the online format is a familiar format for the target population.

The online format offers many benefits but the literature and consultations acknowledged that families are either unaware of their learning needs or feel overwhelmed with the amount of new knowledge they are expected to acquire. At the same time, families often refer to their experience as a journey; the literature identified specific stages within this journey (Dunn et al., 2006; Goldstein, 2006; Melnyk et al., 2006; Staniszewska et al. 2012). Current FHA NICU family education, therefore, was organized by plotting topics that relate to each stage of the NICU journey: prenatal, admission, early days, growing and developing, discharge, and at home. Accordingly, families will be directed to topics that relate to their stage of the NICU journey. This also relates to the aforementioned need to ensure a family directed approach. For example, families who are future orientated will be able to review topics within all stages whereas other families will prefer to focus only on the topics within their current stage.

It is expected, therefore, that families will continue to access the online guide throughout their journey, but families consistently refer to their experience in the NICU as unfamiliar and demanding. To offer them some semblance of familiarity, uniform subtopics for each stage in the NICU journey were created: what to expect, health challenges, helping your baby, developmental care, and self-care. In other words, once

families select a stage along the NICU journey, they will consistently be introduced to topics that may help them navigate through potentially challenging areas.

Appendix B demonstrates how the online guide is organized using the NICU journey and how the topics within each subtopic are distributed. Each subtopic is supported by the evidence gathered from the needs assessment. The subtopic of what to expect aims to lessen the impact of the NICU by helping families become more familiar with what they may be observing or anticipating. For example, the literature identifies that families often describe the NICU environment as unfamiliar, intimidating, and overwhelming, so providing families with descriptions of the NICU environment and routines will be included in the prenatal stage of this section (Aagaard & Hall, 2008; Charchuk & Simpson, 2005; Gavey, 2007; Grosik et al., 2013; Lundqvist et al., 2007; Pepper et al., 2012). In the growing and developing stage, on the other hand, information about milestones, immunizations, and hearing screens will be included.

The health challenges subtopic, however, aims to help families understand their infant's clinical situation. For example, during the prenatal stage, information about why a baby requires NICU care will be included whereas during the early days stage the complications in the NICU will be described. This addresses the fact that families identified the need to have information that will help them make decisions (Arockiasamy et al., 2008; Cleveland, 2008; Heinemann et al., 2013; Pepper et al., 2012; Smith et al., 2012).

The subtopics on helping your baby and developmental care were created to offer families information on the importance of being involved in the care of their infant and how they can participate. This relates to the fact that families describe feeling helpless

and unaware of the importance of their contributions (Grosik et al., 2013; Hollywood & Hollywood, 2011). The literature also indicates that parents often find it difficult to attain their parental role when their infant is in the NICU (Aagaard & Hall, 2008; Cleveland, 2008; Lundqvist et al., 2007; Turan et al., 2008; Wigert et al., 2006). Topics included in these sections, therefore, focus on breastfeeding, pumping, understanding their infant's behaviour and interacting with their infant. For example, during the prenatal stage information about infant feeding and an introduction to developmental care is included, whereas in the admission stage information about expressing and storing breastmilk and skin to skin care are included.

The last sub-topic, self-care, aims to increase families' awareness of effective coping strategies. Several coping strategies, such as promoting positive supportive relationships, self-learning, and journaling, were identified within the needs assessment (Charchuk & Simpson, 2005; Cleveland, 2008; Gavey, 2007; Heinemann et al., 2013; Mundy 2010; Obeisat & Hweidi, 2014; Pepper et al., 2012; Smith et al., 2012; Turan et al., 2008). For example, topics included in the growing and developing stage include information about baby blues, whereas in the at home stage, information about time for yourself at home and first days at home with your baby will be included.

To provide further clarity on how the content will be presented, an example of the completed prenatal stage of the guide is presented in Appendix C. This sample not only demonstrates the structure of the guide but it also details the links to which families will be directed. It is important to note that once the guide is uploaded onto the website these links will be portrayed differently. Families will simply be alerted to a link when the words on the website are highlighted. They are presented this way in the appendix to

demonstrate how current FHA NICU family education is incorporated into the online guide.

It is evident that the online format and structure is advantageous in many ways, but some challenges remain. The needs assessment identified that families prefer a variety of formats but currently the online guide only focusses on written material (Aagaard & Hall, 2008; Arockiasamy et al., 2008; Burnham et al., 2013; Cleveland, 2008; Smith et al., 2012). The online format, however, has the ability to accommodate videos and pictures when they become available. In addition, the online format primarily targets families and not HCPs, although one of the objectives for this project was to augment their teaching. As a result, a one page pamphlet that highlights the online guide's website address and delineates what and where topics are located on the website will be created. HCPs will be able to use this pamphlet to direct families to the website. For example, if a family member has a breastfeeding question the HCP can answer the question and then use the pamphlet to direct them to the appropriate topic on the website. An example of a similar pamphlet that was created for perinatal and postpartum education is portrayed in Appendix D. This pamphlet displays their web address and content within their website.

Finally, families without internet access will not be able to access the online guide. There is, however, a resource called the neonatal checkpoint. The neonatal checkpoint is an online resource that NICU HCPs already use to access policies, manuals, and updates. FHA NICU family education is also available on the neonatal checkpoint but the content of this resource is now dated. The neonatal checkpoint will be updated to reflect all available FHA NICU family education to ensure HCPs have a centralized location to access family education. HCPs, therefore, will have easy access to family

education and print applicable topics for families who have limited access to the internet. At the same time, HCPs will also have access to the online guide and be able to print directly from the website. HCPs will also be able to use these tools to augment their teaching by printing off material that relates to families' questions or concerns. Two snapshots of the neonatal checkpoint appear in Appendix E.

### **Next Steps, Implementation, and Evaluation**

It is anticipated that centralizing and organizing FHA family education will benefit both families and HCPs. However, seven steps remain and they must be completed prior to implementing the guide. This step-by-step approach adheres to the principles of formative evaluation. Formative evaluation can be described as requesting and receiving feedback prior to implementation in order to assess the merits of the planned program (McKenzie, Neiger, & Thackeray, 2013). The next steps, therefore, focus on ensuring the content of the website is appropriate, creating a tool for HCPs, and updating the neonatal checkpoint. A brief summary of these steps will be provided in this report but a comprehensive description of these steps with a proposed timeline is presented in Appendix F. Following successful completion of these seven steps attention will focus on the implementation and evaluation plans.

#### **Next Steps**

At present, the team has completed the prenatal section of the website and thus the next step will be a formative evaluation. This will involve obtaining feedback on the prenatal section of the website from the entire FHA NICU team and NICU families. Feedback from the FHA NICU team will be obtained via email request and during presentations at the regional leadership meeting and clinical practice committee meeting.

Feedback from NICU families will be obtained through informal consultations. Once the information is gathered, the team will meet to discuss the results and, if necessary, revise the content and structure of the website. Upon completion of this step in the evaluation process, the prenatal section will serve as a template for the other five stages, which will in turn enable the development of the remaining webpages. The team will then revise these sections prior to obtaining further feedback from the entire FHA NICU team and families. Once again, the team will meet and consider the feedback and complete any necessary revisions.

Once the website content and structure is fully completed the focus will shift towards ensuring that HCPs have the requisite tools and understandings. As previously mentioned, a pamphlet that indicates what and where specific topics are located on the website will be created. When the website and pamphlet are completed, the team will also ensure that all available online family education materials are uploaded onto the neonatal checkpoint.

### **Implementation and Evaluation**

The implementation and evaluation plans for this project were developed by adapting the Center for Disease Control (CDC) Framework for Program Evaluation in Public Health (see Appendix G). The CDC defines evaluation as “the systematic collection of information about the activities, characteristics, and outcomes of programs to make judgments about the program, improve program effectiveness, and/or inform decisions about future program development” (U.S. Department of Health and Human Services Centers for Disease Control and Prevention ([U.S. HHS CDC], 2011, p. 3). This



framework not only recognizes the importance of using evaluation results to direct improvements, but also guides program implementation.

There are a total of six steps involved in the implementation and evaluation of the FHA NICU family education online guide: describe the program, engage stakeholders, focus the evaluation design, gather credible evidence, justify conclusions, and reflect, recommend, seek feedback, and disseminate (U.S. HHS CDC, 2011). The actions within these steps were selected based upon understanding and applying the evaluation standards: utility, feasibility, propriety, and accuracy (U.S. HHS CDC, 2011).

Descriptions of how these standards support each step are detailed in the plan (see Appendix G). In general, these standards ensure the plans are managed by credible personnel that acknowledge and engage stakeholders, employ an EBP, realistic, and ethical approach, and verify results are valid, reliable, inclusive, accurate, and communicated (Canadian Evaluation Society [CES]), 2014).

The aim of the first step is to develop a clear, concise, and inclusive description of the entire project. Creation of a logic model and vision statement accomplishes this objective and will facilitate many of the activities throughout the implementation and evaluation of this project (see Appendix H). The vision statement offers a comprehensive description of the project's background, mission, and goals (Taylor-Powell, Jones, & Henert, 2003). For this project, therefore, the vision statement incorporates background knowledge of FCC, an assessment of current family education materials, and the project's mission statement and goals. The logic model, however, is a structured and graphic method that illustrates the project's inputs, outputs, and outcomes (McKenzie et al.,

2013). Inputs describe the project's resources, while outputs are the activities completed, and outcomes are the goals (U.S. HHS CDC, 2011).

The second step focuses on identifying individuals involved throughout the program planning process, participants of the program, or anyone else involved in applying the evaluation results (U.S. HHS CDC, 2011). The stakeholders for this project include NICU and perinatal HCPs and NICU families. It is expected that these key stakeholders will help ensure that the guide is reliable, implemented, endorsed, and supported (U.S. HHS CDC, 2011). In order to facilitate the important responsibilities of the stakeholders, engaging presentations, emails, and posters will be prepared and a launch date will be selected.

The third step is to focus the evaluation design, which for this project will involve conducting a summative evaluation. An assessment of the website traffic before and after implementation will be conducted. In addition, informal consultations with NICU HCPs and families will focus on the informational needs of families as well as the accessibility, consistency, and content of education. Evaluating the effectiveness of this project will help to validate the employment of an FCC approach.

The fourth step will involve organizing and gathering credible evidence for the evaluation. In order to accomplish this, it is important to select a manager that will direct all aspects of the evaluation, such as expenses and ethics approval (U.S. HHS CDC, 2011).

The fifth step will center on interpreting the data and communicating the findings in ways that convey meaning for all stakeholders (U.S. HHS CDC, 2011). For this project it will be important to reflect on the principles of FCC when analyzing the data.

Further reflection is required during the final stage of the evaluation plan along with recommendations, feedback, and dissemination. The purpose of the final stage is to identify how the evaluation results will be used, consider the feedback from all stakeholders, and communicate the results (U.S. HHS CDC, 2011). Completion of these tasks has great value as they not only recommend improvements that need to be made but also help to clarify the knowledge gained. Once this project's effectiveness is confirmed, it will then be important to disseminate the results. Thus, the impact of a program evaluation extends beyond the program and aims to enhance the greater body of knowledge. This brief, evidence based, description of an organized and inclusive implementation and evaluation plan demonstrates an appreciation for the responsibilities involved in developing credible programs.

### **ANP competencies**

Planning effective programs requires the expertise possessed by nurses in advanced nursing practice (ANP) roles. Furthermore, program development, implementation, and evaluation skills are enhanced through education, application, and appraisal. Reflecting upon how this project enabled me to demonstrate the Canadian Nurses Association's (CNA) ANP competencies is a constructive activity that will further my professional growth. The four ANP competencies outlined within CNA's "Advanced Nursing Practice: A National Framework" (2008) are: clinical, research, leadership, and consultation and collaboration. These competencies encompass the knowledge and abilities that are necessary for ANP roles and exemplify the characteristics exhibited in ANP.

Clinical competencies include: integrating clinical experience and supporting decisions with evidence, creating and delivering programs that educate families and health care professionals, and understanding the complexities of human behavior. Clinical competency relates to this project by recognizing my extensive experience and knowledge in neonatal nursing. Proficiency in this specialized area also offers an increased familiarity with the NICU's impact on families as well as the influence of FCC. For example, neonatal nurses not only care for NICU infants but they also help families cope with this stressful experience. Helping families cope provides nurses with a greater understanding of their needs which can then be applied to the development of family education programs. In addition, completion of consultations resulted in valuable data and portrayed my knowledge on the complexities of human behaviour. Furthermore, completing a needs assessment demonstrates another clinical competency, EBP. Finally, I illustrated clinical competence throughout this project by demonstrating how to incorporate FCC into practice; a growing body of knowledge.

Research competencies are related to clinical competencies but are specified as the abilities to evaluate, disseminate, and apply research. My research competencies are evident throughout the planning, development, and implementation phases of this project. First, I illustrated evaluation skills by identifying a project that benefits FHA and fulfills the mission of the department. My knowledge about program development models and application of the Generalized Model for this project exemplifies my research competencies. I also performed and completed a comprehensive needs assessment which demonstrates research competencies, such as developing criteria and performing the literature search as well as critiquing and analyzing the selected articles. Moreover,

collecting, managing, and analyzing data from the consultations as well as identifying key stakeholders and acquiring resources during the environmental scan represent additional skills that demonstrate my research competency within this project.

During planning and development of this project, research competency was demonstrated when I interpreted the needs assessment results and applied them to the development of the FHA online NICU family education guide. Finally, during the evaluation phase of this project, I will disseminate the results and identify the project's contributions. These activities will also demonstrate my research competency. For example, the evidence suggests that FCC is highly valued but difficult to incorporate into practice (Gooding et al., 2011; Mikkelsen & Frederiksen, 2011). One of the goals of this project, therefore, is to demonstrate and disseminate the incorporation of a FCC approach to the FHA online NICU family education guide.

The importance of research competencies is clear, but nurses in ANP roles also possess valuable leadership skills to ensure the public receives high quality care and organizations foster a culture of EBP. Leadership competencies include supporting, counselling, advocating, understanding, and communicating skills. In relation to this project, when I founded, organized, and directed the FHA NICU family education shared work team I had the opportunity to demonstrate many leadership skills. For example, when I planned the team's meetings and supported and guided the team throughout the project I demonstrated many of the aforementioned skills. Communication skills were not only exhibited when I articulated the program plan and concisely explained the needs assessment results at the team's meetings but, I also exhibited these skills during the informal consultation conversations. Throughout this project I also appreciated and

advocated for NICU families and HCPs. The decisions I made throughout this project were supported by reflecting on the principles of FCC and interpreting and applying the evidence. Promoting the use of EBP, therefore, is another example of my leadership skills that relate to this project. Finally, the fact that I identified the need to improve patient education in FHA NICUs demonstrates my motivation to improve the quality of care.

Consultation and collaboration competencies can also be associated with leadership competencies, as they are described as supporting patients and their families through the possession of strong communication skills that facilitate coordination with the health care team. In addition to application of theoretical knowledge, the other skills that relate to this competency include intuitiveness, cooperation, organization, articulation, enthusiasm, and promotion of change. I collaborated throughout all the phases of this project. Initially, I identified and invited key stakeholders to contribute to and support this project. Also, strong attendance at the team meetings and the receipt of an abundance of email feedback demonstrates my attainment of the team's respect and commitment. Meanwhile, when I directed and delegated tasks to the team, such as collecting and organizing current family education, I exemplified effective teamwork. Lastly, I managed conflicting opinions, as differences emerged between the key stakeholders. As a result of the needs assessment, however, I was able to substantiate the decisions made. This not only provided me with confidence to advocate for the needs of NICU families but it also exemplifies the benefits of EBP during consultations and collaborations.

Reflecting upon the four ANP competencies not only provides me with assurance that I appropriately planned this project but it acknowledges that nurses in ANP roles possess valuable knowledge and abilities. Indeed, throughout this project, I demonstrated

many of these skills but, at same time, there remain skills that I could refine. For example, further cultivation of research and communication skills will enhance the success of subsequent projects. Also, gaining a greater understanding of mentorship may improve my delegation and augment my productivity in future projects. Overall, gaining more experience in program development, implementation, and evaluation will build my confidence. It is anticipated that with increased confidence I will be motivated to engage in future projects that promote improvements and aim to increase the quality of patient care. My inspiration to pursue future projects may also be accomplished by keeping up to date on current evidence.

### **Conclusion**

This practicum illustrates the process of developing, implementing, and evaluating the FHA online NICU family education guide. Mission and objectives were created and a comprehensive needs assessment was completed. The literature, consultations, and an environmental scan facilitated a greater understanding of the needs of NICU families and greater insight into the features that contribute to the effectiveness of an education program. Next, the guide was created by incorporating the needs assessment results. With the prenatal stage template page complete the next steps for this project have been determined. Moving forward, it is imperative that feedback is obtained from key stakeholders, such as NICU families, regarding the structure and content of the online guide. Once the guide and accompanying resources are complete, the implementation and evaluation plans will be initiated. These plans are comprised of six steps that were guided by the evaluation standards. Lastly, reflection upon how this project demonstrates the

CNA ANP competencies acknowledges the skills involved in developing credible programs.

This project, therefore, recognizes that families with an infant in the NICU experience a range of emotions and employ varied coping strategies for dealing with these emotions. Thus, offering families organized, consistent, reliable, and family directed education aims to decrease families' stress, increase their confidence, improve attachment, and support parental role attainment. In order to promote the achievement of these goals a FCC, evidence-based approach was employed that guided the development, implementation, and evaluation of the FHA online NICU family education guide. Ultimately, completion of this project validates the value of FCC and demonstrates activities that can be employed in an effort to uphold the principles of FCC.



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**Appendix A**

**Needs Assessment for a Neonatal Intensive Care Unit Family Education Guide**



# NEEDS ASSESSMENT FOR A NICU FAMILY EDUCATION GUIDE

Needs Assessment for a Neonatal Intensive Care Unit Family Education Guide

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### Abstract

**Background:** Family centered care (FCC) is a philosophy that many neonatal intensive care units (NICUs) adopt, including NICUs within British Columbia's Fraser Health Authority (FHA). Evidence is limited regarding the incorporation of FCC into practice but providing NICU families with education is one approach that supports the principles of FCC. **Purpose:** A needs assessment was conducted to validate and facilitate the development of a FHA NICU family education guide. **Methods:** The methods used to conduct a comprehensive needs assessment were: (a) literature reviews of NICU family needs and NICU family education programs; (b) consultations with the FHA NICU health care team, FHA NICU families, and a FHA patient education consultant; and (c) an environmental scan of current FHA NICU family education. **Results:** The literature review of NICU family needs and consultations pinpointed: (a) families' emotions and changing needs throughout their NICU journey; and (b) families' coping strategies. The literature review of NICU family education programs and consultations identified: (a) preferred formats and content of education; (b) the importance of employing evidence based practice during program development; and (c) developing programs that foster an individualized, parent directed, and FCC approach. The environmental scan validated the need to organize FHA family education as current education is inconsistent, disjointed, unavailable, and unit specific. **Conclusion:** This needs assessment supports and informs the development of a FHA NICU family education guide which aims to support the principles of FCC by ensuring that education throughout the NICU journey is accessible, consistent, reliable, individualized, and parent directed.

## NEEDS ASSESSMENT FOR A NICU FAMILY EDUCATION GUIDE

*Keywords:* neonatal intensive care (NICU), family, family centered care (FCC), parenting, education

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### **Introduction**

Family centered care (FCC) (NICU) is a highly valued approach in neonatal intensive care units (NICUs). FCC is founded upon the supposition that outcomes are improved when families are considered partners and included in all aspects of care (Gooding et al., 2011). Principles of FCC include ensuring respect and dignity, information sharing, participation, and collaboration (Griffin, 2006). The provision of NICU family education is one area that supports the principles of FCC and demonstrates the benefits of using this approach.

Educating NICU families has the potential to benefit not only families but NICU infants and health care organizations. There is evidence to suggest that NICU family education decreases length of stay, improves outcomes, increases family satisfaction, and facilitates collaboration among health care professionals (Brett, Staniszewska, Newburn, Jones, & Taylor, 2011; Gonya & Nelin, 2012; Leonard & Mayers, 2008). Additional benefits for families of NICU family education reported in the literature include stress reduction, increased confidence, and increased visitation (Brett et al., 2011; Smith, Deai, Sira, & Engelke, 2014). The benefits of NICU family education and its relevance to FCC are well-articulated in the literature but incorporation of FCC practices is haphazard with limited evidence to support the development and effectiveness of programs within various NICU settings. As a result, emphasis should be placed on the development, implementation, and evaluation of comprehensive NICU family education programs, grounded in the principles of FCC.

The five NICUs within British Columbia's Fraser Health Authority (FHA) are committed to ensuring that FCC is incorporated into all areas of practice. The

## NEEDS ASSESSMENT FOR A NICU FAMILY EDUCATION GUIDE

development of a NICU family education guide is proposed for this practicum. The mission of this project is to ensure that education offered to families within FHA NICUs meets the needs of families throughout their NICU journey and supports the principles of FCC. The goals of this project are to facilitate families' awareness of education and to ensure education is accessible, relevant, and consistent. This guide also aims to increase NICU parents' confidence, improve attachment, support NICU parent role attainment, and decrease NICU parents' stress. Finally, it is felt that this guide will assist in identifying the gaps within FHA NICU family education. To facilitate the success and appropriateness of this guide, as well as its adherence to the principles of FCC, a needs assessment was conducted. Overall, this needs assessment intends to validate, facilitate, and provide a solid foundation for the planning and development of a FHA NICU family education guide.

A needs assessment is the process of collecting and analyzing data with the aim of developing a greater understanding of needs, assets, and limitations of a target population (McKenzie, Neiger, & Thackeray, 2013). It is recommended that a needs assessment include a combination of primary (consultations with key stakeholders) and secondary (literature review) data collection. During this practicum, the collection of primary data included informal consultations with FHA NICU families, the FHA NICU health care team, and a FHA patient education consultant. Also, an environmental scan was completed and involved the collection of existing resources within FHA. Two literature reviews represented the main source of secondary data collection. The first literature review focused on NICU families' informational needs and experiences. The second review focused on NICU family education programs.



## NEEDS ASSESSMENT FOR A NICU FAMILY EDUCATION GUIDE

The following report provides a discussion of the needs assessment designed for the development of a FHA NICU family education guide. The first section presents the literature reviews and includes an overview of the methodological approach to the search strategy, criteria for article selection, and critical appraisal of the selected articles. An evidence summary table of selected articles was created (see Appendix A). The findings from the two literature reviews, NICU family needs and experiences and NICU parent education programs, are presented separately. The second section presents a synopsis of the informal consultations and environmental scan. This section, therefore, includes descriptions of the setting, participants, methods, data collection, and results of the informal consultations with the aforementioned stakeholders and environmental scan. The third section presents a brief discussion of the common themes that emerged from the analysis of findings from the primary and secondary data. Synthesis of these findings focuses on substantiating and informing the development of the proposed FHA NICU family education guide.

### **Secondary Data: Literature Reviews**

Secondary data consists of information gathered by other individuals (McKenzie, et al., 2013). There are several sources of secondary data, but for the purposes of this needs assessment, data from the literature was collected and analyzed. First, the methodology used to obtain and select the articles will be described and the tools used to determine the articles' reliability and validity will be identified. Then, for each literature review, an integrative discussion regarding the themes within the literature will be conducted.

### **Methodology**

Two comprehensive electronic literature searches using the Medline, EMBASE, and CINAHL databases were completed. First, a literature review related to NICU parents' information needs and experiences was conducted using a combination of search words: neonatal intensive care unit, parents, experience, information, and consumer health information. Secondly, a literature review was conducted on NICU family education programs using a combination of search words: neonatal intensive care unit, parents, and patient education. Inclusion criteria for both searches consisted of English language articles published between 2005-present. The selection of articles for both searches included a review of abstracts, retrieval of articles addressing the phenomenon of interest and scanning the reference lists of retrieved articles for additional articles meeting the search criteria.

A comprehensive critique of the qualitative research was guided by the critical appraisal skills programme (CASP) (Critical Appraisal Skills Programme, 2013). This appraisal tool includes ten screening questions that directs critique of qualitative research in a systematic way. The quantitative research, including mixed methods research, was guided by the Public Health Agency of Canada's Infection Prevention and Control Guidelines: Critical Appraisal Tool Kit (Public Health Agency of Canada [PHAC], 2014). This tool kit provides a consistent, logical, and organized method of identifying study design and assessing the strength and quality of research articles. Evidence summary tables for both literature searches were created (see Appendix A) and provide an overview of the articles' objectives, designs, theoretical backgrounds, key findings, strengths and limitations, and overall ratings.

### **Analysis of NICU Family Needs and Experiences**

The key question that guided this literature review was: what are the experiences of parents' whose infant is admitted to the NICU? Specific emphasis, however, was placed on the following questions: what factors elicited positive and negative experiences and what information did families require during their infant's NICU admission, did families' experience changing needs during their infant's NICU admission? These questions were selected as it is felt that they relate well to the development of a NICU family education guide. There is a great deal of literature available that aims to gain a greater understanding of NICU families' needs and experiences but not all the research was appraised as having a strong design with high quality.

In total, twenty articles were selected for this review. Thirteen of these articles were qualitative design, five were quantitative design, three were literature reviews, one was a mixed methods design, and one was a case report. The qualitative research employed a descriptive, interpretive, or grounded theory approach whereas the quantitative research used only a descriptive approach. The literature reviews were comprised of a metatynthesis, systematic and narrative review. The evidence summary tables in Appendix A illustrate the appraisals of all the research in which the study design and quality are described.

The studies appraised using the CASP tool are represented in table A1. Six qualitative studies were rated as having a strong design with high quality due to the fact that they had a well-defined purpose, appropriate and justified methodology supported by theory, ethics approval, and use of direct evidence with implications to nursing practice. The studies appraised using the PHAC tool are represented in table A2. As all of the

quantitative studies were descriptive design the PHAC tool recommends that this research should be rated as weak as it is not intended to test hypotheses (PHAC, 2014). Four studies, however, were appraised with high quality as they had a focused research question, excellent response rate, appropriate data collection techniques, credible surveys, ethics approval, appropriate use of statistics, and used direct evidence with implications to nursing practice.

Upon completion of the literature appraisal the twenty selected articles were read and key points were highlighted. Then, articles were read for a second time and the key points were categorized by grouping commonalities and patterns. Ultimately, six themes emerged upon analysis of the literature: response, support, knowledge acquisition, involvement, individualized needs, and NICU journey.

**Response.** An infant's admission to the NICU evokes a range of responses from family members. In fact, a NICU admission has been identified as a "traumatic stressor" (Dunn, Reilly, Johnston, Hoopes, & Abraham, 2006, p. 36) by the American Psychology Association Diagnostic and Statistical Manual. Families' responses are affected by their emotional reactions, perceptions of health care providers, and impact of the NICU environment.

Developing a greater understanding of the types of emotions experienced by families is very important. Families often experience a high level of stress and shock (Heinemann, Hellstrom-Westas, & Hedberg-Nyqvist, 2013; Sweet & Mannix, 2012; Turan, Basbakkal, & Ozbek, 2008). Most emotions experienced are negative and include feelings of uncertainty, fear, grief, sadness, and worry which results in emotional and physical exhaustion (Heinemann et al., 2013). In spite of this, one positive emotional

response noted with the literature is hope (Charchuk & Simpson, 2005; Mundy, 2010; Pepper et al., 2012). For example, despite the stress and uncertainty that encompasses NICU families' experiences, parents remain hopeful that they will bring their infant home.

The evidence also suggests that mothers and fathers have a tendency to experience different emotional reactions. Mothers describe feeling powerless, guilty, insufficient, insecure, unsure, estranged, depressed, and useless (Aagaard & Hall, 2008; Wigert, Johansson, Berg, & Hellstrom, 2006; Pepper, Rempel, Austin, Ceci, & Hendson, 2012). Fathers' responses, on the other hand, relate to lack of control and conflicting emotions (Arockiasamy, Holsti, & Albersheim, 2008; Deeney, Lohan, Spence, & Parkes, 2012; Lundqvist, Westas, & Hallstrom, 2007). Fathers describe experiencing negative feelings such as resentment, distractedness, helplessness, surrealness, uncertainty, being discriminated against versus, positive feelings such as courageousness, protectiveness, and resiliency (Arockiasamy et al., 2008; Deeney et al., 2012; Hollywood & Hollywood, 2011; Lundqvist et al., 2007). The evidence suggests that fathers, while experiencing a similar number of negative emotions, exhibit more positive emotions than mothers.

The emotional response of families' is influenced by how they perceive their interactions with health care providers (HCPs) and their observations of HCPs actions. Feelings of being overlooked, lack of control, isolation, and mistrust generate negative feelings (Charchuk & Simpson, 2005). Similarly, families' interpretation of HCPs' actions may generate a negative response (Burnham, Feeley, & Sherrand, 2013; Cleveland, 2008; Heinemann et al., 2013; Sweet & Mannix, 2012). For instance, if families interpret the actions of HCPs' as uncaring their stress level may increase

(Mundy, 2010). Families also struggle with the authority HCPs have as they are the primary care giver of their infant (Cleveland, 2008; Deeney et al., 2012). Having an infant in the NICU is definitely not a natural experience for parents as they had been preparing and expecting to be the main care provider for their infant.

The NICU environment also evokes negative feelings. Parents often describe the NICU environment as unfamiliar, intimidating, overwhelming, isolating, feminine, and helpless (Aagaard & Hall, 2008; Charchuk & Simpson, 2005; Gavey, 2007; Grosik et al., 2013; Lundqvist et al., 2007; Pepper et al., 2012). The experience of NICU families certainly relates well to the “culture shock that a traveler may experience” (Pepper et al., 2012, p.308). Parents also view the NICU environment as a major barrier to their ability to attain a the parental role and bond with their infant (Aagaard & Hall, 2008; Cleveland, 2008; Lundqvist et al., 2007; Turan et al., 2008; Wigert et al., 2006).

**Support.** NICU families’ need for support is clear. Parents identify a variety of potential sources of support such as spouses, family, friends, other NICU families, and NICU HCPs (Aagaard & Hall, 2008; Arockiasamy et al., 2008; Cleveland, 2009; Deeney et al., 2012; Grosik et al., 2013; Mundy, 2010; Pepper et al., 2012; Smith, SteelFisher, Salhi, Shen, 2012; Turan et al., 2008). Many NICU families describe relationships with HCPs as being the most supportive due to their consistent presence and knowledge (Aagaard & Hall, 2008; Cleveland, 2008; Pepper et al., 2012). Nonetheless, there are positive and negative aspects to all relationships. For example, when family and friends are able relate to the experience because of a medical background or previous NICU experience they tend to be more supportive (Smith et al., 2012). Conversely, family and friends are also described as being encumbering (Smith et al., 2012).

Reports of qualitative, descriptive studies of NICU families, note that participants identified strategies for promoting positive supportive relationships. These approaches include providing comfort, empathy, honesty, confidence, encouragement, and hope (Charchuk & Simpson, 2005; Cleveland, 2008; Heinemann et al., 2013; Mundy 2010; Obeisat & Hweidi, 2014; Pepper et al., 2012; Turan et al., 2008). Specific strategies for ensuring positive relationships with HCPs include consistency, trust, and respect (Aagaard & Hall, 2008; Cleveland, 2008; Hollywood & Hollywood, 2010; Pepper et al., 2012; Sweet & Mannix, 2012).

**Knowledge acquisition.** The evidence suggests that the ability to acquire knowledge is an important source of support or coping mechanism for NICU families. Moreover, knowledge acquisition is a complex but vital requirement for families due to the unfamiliar and uncertain characteristics of the NICU experience. The majority of the literature focuses on how NICU families acquire information, why information is sought, and what information is needed.

There are many ways to gather information but families reiterate that they prefer to receive consistent and easy to understand information that is regularly repeated and reinforced (Cleveland, 2008; Heinemann, et al., 2013; Hollywood & Hollywood, 2010; Obeisat & Hweidi, 2014; Pepper et al., 2012). Information may be acquired through formal and informal methods such as written material, classes, hands-on experience, and chatting (Aagaard & Hall, 2008; Arockiasamy et al., 2008; Burnham et al., 2013; Cleveland, 2008; Smith et al., 2012). Families' need to seek information that not only helps them cope with the NICU experience but also assists them with decision making

and regaining control (Arockiasamy et al., 2008; Cleveland, 2008; Heinemann, et al., 2013; Pepper et al., 2012; Smith et al., 2012).

The type of information that families describe as important includes medical updates that notify them of changes or improvement in their infant's health status, care plan, and/or expected outcomes (Mundy, 2010; Pepper et al., 2012; Smith et al., 2012; Turan et al., 2008). Other topics on which parents may need to receive information include NICU routines and technology, recognition of infant behaviour, and infant feeding, sleeping, bathing, and positioning (Burnham et al., 2013).

**Involvement.** Another useful coping method, in the literature, associated with knowledge attainment includes families' awareness of the benefits of participating in the care of their infant (Heinemann et al., 2013; Lunkqvist et al., 2007; Smith et al., 2012). Indeed, when families involve themselves in their infant's care they experience less fear and stress and gain confidence, control, and hope (Burnham et al., 2013; Heinemann et al., 2013; Hollywood & Hollywood, 2010; Smith et al., 2012). Accordingly, families classify having the ability to participate in their infant's care as a very important need (Mundy, 2010).

Families' note that the more they participate in their infant's care the more motivated they are to attain a parental role (Heinemann et al., 2013; Lunkqvist et al., 2007). Further, becoming more involved also serves to increase family visitation (Heinemann, et al., 2013). Families also identified that they are encouraged to become more involved when HCPs provide them with assurance and actively engage them in the care of their infants (Cleveland, 2008; Heinemann, et al., 2013; Obeisat & Hweidi, 2014).



**Individualized needs.** The literature clearly describes the diverse needs and varied coping skills of NICU families and it is frequently suggested that HCPs should provide an individualized approach (Arockiasamy et al., 2008; Burnham et al., 2013; Heinemann, et al., 2013; Smith et al., 2012). For example, families' perceptions of when they will be ready for discharge may differ from those of HCPs but once expectations are clarified individualized care plans can be created (Burnham et al., 2013). When HCPs work with families to determine their specific needs their ability to provide optimal support is improved. Another example of this approach is when HCPs provide families with information that solely pertains to their infant's specific health challenges (Arockiasamy et al., 2008; Burnham et al., 2013). In conclusion, HCPs should find it easier to create personalized care plans that incorporate each family's unique coping strategies (Smith et al., 2012).

**NICU journey.** Families' needs are not only diverse but are constantly changing during the NICU journey (Aagaard & Hall, 2008; De Rouck & Leys, 2009; Grosik et al., 2013; Lunkqvist et al., 2007; Redshaw & Hamilton, 2010). One identifiable experience is the transition to parenthood for mothers (Aagaard & Hall, 2008). Correspondingly, Lunkqvist et al. (2007) describe a father's NICU journey as progressing from feelings of distance to proximity.

Families have also described their experience as one of increasing comprehension of the NICU environment and their infant's medical status. This aspect is captured in descriptions of progressing from watchers, to learners, to doers (Redshaw & Hamilton, 2010). Similarly, the illness trajectory has often been used to demonstrate how an infant's changing medical status impacts a family's learning needs (De Rouck & Leys, 2009).

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Recognizing that families' experiences are a journey or progression is important because HCPs need to appreciate that families' informational needs are constantly changing. Moreover, awareness that families' changing needs relate to the step of the journey in which they are currently engaged is also important.

### **Summary of NICU Family Needs and Experiences Literature Review**

The literature offers a greater understanding of families' NICU experiences. Concentrating on the factors that elicit positive and negative experiences, identification of families' information requirements, and families' changing needs throughout their NICU journey facilitated a focused analysis of the literature that will be applied to the development of a NICU family education guide. It is understandable that families experience a great deal of stress when their infant is admitted to the NICU and this experience evokes a range of emotional responses and varying perceptions towards HCPs. Families' negative and positive responses are described as well as specific differences between mothers' and fathers' response. In an effort to manage such a stressful experience families employ unique coping methods. Positive supportive relationships, consistent, reliable, and repeated information, and participation in their infant's care are potential coping strategies that may assist families cope. It is important to realize, however, that these coping strategies are not effective for all families and may actually be a further source of stress. In addition, families employ different coping strategies throughout their NICU journey as their needs are constantly changing. As a result, individualizing families' care supports families' specific coping strategies and their changing needs throughout their NICU journey.

### **Analysis of NICU Family Education Programs**

The principal question that guided this literature review was: what aspects contribute to a successful NICU parent education program? Specific focus, however, was placed on the following questions: how were the principles of FCC incorporated into the programs and what formats and topics were included in the programs? These questions aim to guide the development of the FHA NICU family education guide. The literature available that aims to gain a greater understanding of NICU education programs was appraised; not all the research was appraised as having a strong design with high quality.

A total of thirteen articles that met the search criteria were selected. Seven were qualitative, four were quantitative, and two were mixed methods design. The qualitative research designs were a metasynthesis, narrative reviews, and case reports. The quantitative research consisted of randomized controlled trials and analytical design. The articles that employed an analytical approach included, cohort, and interrupted time series studies. The evidence summary tables in Appendix A illustrate the appraisals of all the research in which the study design and quality are described.

The studies appraised using the PHAC tool are illustrated in table A3. Two of the quantitative studies were rated as strong design with high quality due to the fact that they were randomized control design with a focused research question, excellent response rate, appropriate data collection techniques, credible surveys, ethics approval, appropriate use of statistics, and utilized direct evidence with implications to nursing practice. The studies appraised using the CASP tool are represented in table A4. Four of the studies were rated as strong design with high quality or relevancy as they had a well-defined purpose,

appropriate and justified methodology, comparable goals, focus, and values, ethics approval, and use of direct evidence with implications to nursing practice.

Similar to the first literature review, after completion of the literature appraisal the thirteen selected articles were read and the main ideas were highlighted. Then, articles were read for a second time and the major ideas were categorized by grouping commonalities and patterns. The research was varied as some articles include the development, implementation, and evaluation of the program whereas others merely describe the content of the program. Nonetheless, the following themes materialized: planning and evidence based practice (EBP), FCC and program effectiveness, individualized and parent directed approach, and formats and content.

**Planning and EBP.** NICU family education program development requires a multifaceted approach. EBP is demonstrated in numerous programs to support program content and delivery (Bracht et al., 2013; Dusing, Van Drew, & Brown, 2012; Goldstein, 2013; Morey & Gregory, 2012; Schlittenhart, Smart, Miller, Severtson, 2011; Willis, 2008; Staniszweska et al. 2012). For example, EBP was employed to facilitate development of the Parents of Premature Babies Project (POPPY) by integrating knowledge gained from a systematic review of NICU parents' experiences and qualitative study data from interviews and surveys of NICU parents throughout the United Kingdom (Brett et al., 2011; Redshaw & Hamilton, 2010; Staniszweska et al. 2012). Correspondingly, development of the Family Integrated Care (FIC) program was based upon evidence from comprehensive literature reviews of NICU parents' informational needs, education programs, and formats (Bracht et al., 2013).

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There are certainly examples within the literature that denote the use of EBP and its impact during program development but EBP also benefits aspects of program implementation. Melnyk et al. (2010) assessed changes in nurses' beliefs regarding EBP after completion of an eight hour workshop in the Creating Opportunities for Parent Empowerment (COPE) program and EBP. The findings indicated that nurses who completed the workshop were more positive towards EBP than their counterparts who did not attend the workshop (Melnik et al., 2010). These results support the inclusion of EBP education during HCPs' orientation to a NICU family education program.

Another important aspect of program planning noted within in the literature relates to the personnel involved. Specifically, the literature pinpoints program development team members as a factor that appears to impact the relevancy and content of NICU education programs (Bracht et al., 2013; Dusing et al., 2012; Schlittenhart et al., 2011; Staniszewska et al. 2012). NICU HCPs and families are the two groups that are most frequently cited as qualified and desirable members of the program development team. Other valuable members, associated more with program implementation, include program super-users or mentors and program co-ordinators or administrators (Bracht et al., 2013; Dusing et al., 2012; Hurst, 2006; Melnyk et al., 2010; Morey & Gregory, 2012; Willis, 2008). Overall, the literature validates collaboration with NICU families and the application of EBP throughout program development, implementation, and evaluation. Accordingly, inclusion of these aspects in education programs complements the principles of FCC.

**FCC and program effectiveness.** One major purpose for developing NICU family education is to ensure that the principles of FCC are applied to all aspects of care

(Bracht et al., 2013; Dunn, Reilly, Johnston, Hoopes, & Abraham, 2006; Goldstein, 2013; Hurst, 2006; Staniszweska et al. 2012; Willis, 2008). In fact, some of the literature describes the creation of principles or philosophies during program development that strongly resemble the principles of FCC (Bracht et al., 2013; Dunn, Reilly, Johnston, Hoopes, & Abraham, 2006; Hurst, 2006; Staniszweska et al. 2012). Interestingly, the American Academy of Pediatrics and the Canadian Pediatric Society also stress the importance of family involvement in the NICU and suggest that evaluation of family readiness needs should be considered prior to discharge (Committee on Fetus and Newborn, 2008; Jefferies, 2014). Moreover, content and design of parent education is also addressed in these statements.

The literature also endorses incorporation of the principles of FCC into education programs by verifying their effectiveness. The COPE program and a nurse-led prenatal education program have been evaluated for program effectiveness (Borimnejad, Mehrnoosh, Fatemi, & Haghani, 2013; Melnyk, Bullock, Jacobson, Kelly, & Baba, 2010; Melnyk et al., 2006; Morey & Gregory, 2012). Research findings indicate that these types of education programs help decrease maternal stress levels. Further, evaluative data on the COPE program suggests that this type of program decreases length of stay, maternal anxiety, and depressive symptoms as well as increases parental involvement (Borimnejad et al., 2013; Melnyk et al., 2006; Morey & Gregory, 2012). These results support developing a NICU education program that includes a FCC approach.

**Individualized and parent directed approach.** Another frequently discussed topic within the literature is the design of NICU family education programs. Two aspects of design that frequently arise include the program's ability to be individualized and

parent directed (Dunn et al., 2006; Goldstein, 2013; Hurst, 2006; Melnyk et al., 2006; Schlittenhart et al., 2012; Staniszweska et al. 2012; Willis 2008). Goldstein (2013) describes how the NICU care path includes a learning assessment that identifies what information families want to learn and how they want to learn it. This program also enables the parents to learn at their own pace, as learning activities and topics are pinpointed at each stage of the care path (Goldstein, 2013). The design of a NICU family education program, therefore, requires creative formats to incorporate all of the families' needs.

**Formats and content.** A multitude of topics and formats must be considered when developing a NICU family education program. Examples of delivery methods include: written, classes, videos, audiotape, demonstrations, group support, telephone support, journaling, one on one discussion, and web-based programs (Bracht et al., 2008; Dunn et al., 2006; Dusing et al., 2012; Goldstein, 2013; Hurst, 2006; Melnyk et al., 2006; Morey & Gregory, 2012; Schlittenhart et al., 2012). The topics coupled with, the needs of families, help developers select appropriate formats for implementation. In some instances, like the FIC program, adult learning theory was used to help with the selection of appropriate formats (Brach et al., 2008).

Program content is also diverse and dependent on the education program's purpose. The literature and the American and Canadian Pediatric Associations provides examples of program content (Bracht et al., 2013; Committee on Fetus and Newborn, 2008; Dunn et al., 2006; Dusing et al., 2012; Goldstein, 2006; Hurst, 2006; Jefferies, 2014; Melnyk et al., 2006; Morey & Gregory, 2012; Schlittenhart et al., 2012; Willis, 2008). For example, some programs are designed for antenatal education while others

focus only on emotional support (Hurst, 2006; Morey & Gregory, 2012). In order to ensure NICU parents are involved in all aspects of infant care, best practice is to ensure that all family needs are met throughout the entire NICU journey.

The different phases of the NICU journey are also referenced in many NICU family education programs. For example, Morey and Gregory (2012) describe a program that concentrates on the prenatal period, whereas Willis (2008) describes a program that focuses on discharge. Some programs have organized educational topics for parents along the entire NICU journey or during various phases of their infant's stay (Dunn et al., 2006; Goldstein, 2006; Melnyk et al., 2006; Staniszweska et al. 2012). This is evident in Melnyk's (2006) description of COPE which is implemented in four phases (starting two to four days after admission and ending one week after discharge). Comparatively, Dunn et al. (2006) describe the organization of educational topics according to key stages of the NICU journey (stages include preadmission, golden hours, acute, growing stronger, breathing/feeding/growing, transfer, transition to home, post discharge, and bereavement). Although the benefits of this approach are not described in the literature, it may help NICU families minimize feelings of being overwhelmed with too much information while also fostering a parent-directed approach. At the same time, organizing educational topics along the NICU journey may also act as a guide for NICU HCPs, as educating NICU families is one of their many responsibilities.

### **Summary of NICU Family Education Programs Literature Review**

Upon reflection of the literature associated with NICU family education programs it is apparent that there are features throughout the development, implementation, and evaluation stages that contribute to the effectiveness of a program. The benefits of EBP is



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outlined in the literature and validates this needs assessment and the knowledge gained will positively contribute to the development of the FHA NICU family education guide. Research results' regarding the impact of NICU family education programs also endorses the application of a FCC approach. Incorporation of the principles of FCC in education programs is demonstrated in the literature and includes collaboration with families throughout all stages of program development as well as creating programs that families can individualize and control. Accordingly, the literature identifies the importance of education programs using a variety of formats and including a multitude of topics aimed towards meeting the needs of families throughout their entire NICU journey. Finally, it is evident that during the development of education programs consultations with key stakeholders that focus on identifying the experiences, needs, and ideas of the target population play a significant role.

### **Primary Data: Consultations & Environmental Scan**

While secondary data provides a comprehensive overview of NICU family needs and experiences there are notable disadvantages to using this type of data (McKenzie, et al., 2013). Primary data collection provides valuable contributions to the needs assessment by overcoming the limitations of secondary data. This can be achieved, in part, by collecting information directly from the target population and providing detailed descriptions of similar and disparate settings. For the purposes of this needs assessment, priority target populations identified for informal consultations included members of the FHA NICU Health Care Team and FHA NICU families, as well as a FHA patient education consultant. In addition to these consultations an environmental scan was

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conducted and consisted of gathering existing education resources within all of the FHA NICUs.

### **Consultations**

Prior to initiating the consultations, it was important to determine whether research ethic board approval would be necessary. Completion of the Health Research Ethics Authority (HREA) screening tool (see Appendix B) confirmed that the project's focus was directed towards program evaluation and quality assurance than research. To clarify, these consultations do not answer specific research questions. The overall purposes of these consultations entail gaining a greater understanding of FHA families' experiences and establishing connections with stakeholders within FHA. The key question, therefore, that guided these consultations was: what are the experiences of families whose infant is admitted to a FHA NICU? Specific emphasis, however, was placed on the following questions: what are FHA families' informational needs and preferences, was the education that families received effective, and how can the FHA patient education department assist with this project? These questions aim to provide positive contributions to the development of a NICU family education guide.

The three main consultations that occurred were informal discussions with the FHA NICU healthcare team, FHA NICU families, and a FHA patient education consultant. Each consultation will be discussed separately but they will all be described in the same manner. To begin with, the rationale for selecting each consultation will be presented followed by a description of the setting, participants, and methods. Next, the data collection, management, and analysis of each consultation will be explained. Then, a detailed description of the results will be provided. In conclusion, a summary of the

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consultations and their relevance towards the development of the FHA NICU family education guide will be offered.

**FHA NICU health care team.** Members of the FHA NICU family education shared work team were consulted due to their expertise with working and teaching families and their familiarization with the NICU environment. Initial consultations focused on gaining greater insight and understanding of their experiences teaching FHA families. However, consultation with this shared work team will be ongoing to assist with organizing and developing the NICU family education guide. Future consultations with team members will focus on identifying strategies that will facilitate development, implementation, and evaluation of a FHA NICU family education guide.

***Setting, participants, and methods.*** The FHA comprises a large area within the lower mainland of British Columbia; there are five NICUs that serve this entire region. The population of this area 1, 648, 182 with 17, 391 live births (Health & Business Analytics, FHA. 2012). This population is multicultural; 78.7% of the population speak English, 6.5% speak Punjabi, 5.7% speak a combination of Cantonese or Mandarin (Health & Business Analytics, FHA. 2012). The FHA consists of 13 cities with an average income of \$68,641 but 10.8% of the population is categorized as low income (Health & Business Analytics, FHA. 2012). The main differences between the five FHA NICUs consist of variances in acuity, census, layout, and allied health support. Four of the NICUs are open bay layout and only two of the NICUs have full-time allied health support. The smallest NICU has a census of four beds and only has the ability to care for level 1B infants (increased observation). Two of the NICUs care for level 2A infants (acute care); one is an eight bed unit and one is a 10 bed unit. The final two units care for

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level 3 infants (high acuity, multidisciplinary care); one is a 24 bed unit and one is a 28 bed single room care unit.

Initially, permission to create a regional NICU family education shared work team was obtained from all three FHA NICU managers. Once permission was received to form the shared work team an invitation to join the team was sent via FHA email to all NICU employees. The final composition of the shared work team included registered nurses, physiotherapists, occupational therapists, speech language pathologist, access flow coordinator, pharmacist, discharge planning nurse, lactation consultant, and a clinical nurse specialist. Members of this shared work team represent a wide range of professionals yet are not all inclusive. Once the education guide is completed, however, feedback will be obtained from all NICU professionals, including neonatologists, social workers, and managers.

Team members will be invited to attend monthly meetings where information will be collected during face to face discussions. Email will also be used to communicate and gather information from team members. Also, an agenda for each meeting will be created and shared with the team members in advance via email to help team members prepare to discuss the identified topics. Due to irregular work schedules, it was unrealistic to expect all team members to attend each meeting. If members were not able to attend a meeting they had the opportunity to provide feedback remotely by perusing the agenda and submitting their contributions via email.

***Data collection, management and analysis.*** Minutes were written for each monthly meeting as a way of documenting the discussions. Distribution of the minutes occurred via FHA email to ensure all team members were updated on the discussions and

progress. During the first meeting, the purpose behind conducting a needs assessment of FHA NICUs was discussed and agreement to proceed was obtained from all team members. Two guiding questions were asked to help facilitate discussion on team members' experiences with families. In your experience, what have parents told you about their informational needs? What questions do parents consistently ask you? A summary of the responses to both these questions can be found in Appendix C.

**Results.** NICU health care team responses focus mainly on families' knowledge acquisition. The replies were categorized in terms of the six basic questions used to gather information: where, who, when, why, how, and what. It is apparent that the answers to these questions help parents gain a greater understanding of their whole experience. The text that follows presents a brief summary of the team's responses. Throughout this summary the answers to the six aforementioned informational gathering questions will be elucidated.

In general, the team noted that families prefer to receive information at their baby's bedside while seeking information and support from all members of the health care team, especially the neonatologists. Interestingly, the team noted that parents frequently inquire about the rationale for the health care team's decision making. Families also tend to repeat the same questions and are somewhat future-orientated as they consistently ask what to expect. The nature and frequency of families' questions change as their baby progresses and when families become more involved in their infant's care. For example, when a parent starts taking their infant's temperature this prompts them to ask what normal temperatures are for their infant.

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Regardless of the approach used by families to gather information, it is prudent to understand how information and support is provided by the health care team. The team identified numerous approaches, such as reassurance, use of lay terms, written material, classes, one on one discussion, and hands on experience. Additionally, team members were of the opinion that the following measures had positive impacts on families: building confidence, encouraging families to advocate on behalf of their infant, facilitating families' communication with the health care team, and offering suggestions on how best to assume their parental roles.

A large portion of the discussion with the team focused on what types of information families' request. While a summary of suggested educational topics can be found in Appendix C, it is important to note that the team identified differences between mothers' and fathers' needs. Mothers' questions are directed more towards their infant's behaviours and activities whereas fathers' questions relate to their infant's specific health challenges. The team also described specific needs that families have upon arrival in the NICU and how eager parents are to learn but do not necessarily know what topics they need to learn about. Finally, it is apparent that parents simply desire the best for their baby and this is the primary reason they frequently seek the advice of health care professionals.

**FHA NICU families.** There is a great deal of literature available on NICU family needs and experiences but it is important to document the specific needs of the target population. It is also important to determine the priority needs of families within and across FHA NICU sites. That is, is there similarity in needs and their importance? If differences exist what are possible contributing factors?

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***Setting, participants, and methods.*** It was necessary to consult with families from more than one FHA NICU due to the aforementioned differences. As a result, families were approached from three FHA NICUs, the two large tertiary level units and one of the smaller level two units. The two large units were selected as more families could be approached in a short period of time; these families also tend to have more to learn as their infants have greater health challenges. The small level two NICUs, therefore, have different target populations with diverse learning needs and as a result, it is important to explore the needs of these families as well. Inclusion criteria restricted participants to English speaking NICU families. Families were approached during NICU visits and asked to engage in an informal discussion with the researcher.

***Data collection, management, and analysis.*** Informal, face to face, conversations with the families focused on education received, along with additional education needs and personal delivery method preferences. The complete discussion guide can be found in Appendix D. Notes were also taken after the conversations to help analyze the responses, but names were not documented to ensure confidentiality. The responses of FHA NICU families can be found in Appendix E.

***Results.*** Discussions with FHA NICU families indicate that a variety of education and information was provided at various times. A description of the type of information and education families received, when they received it, and families' assessment of the material can be found in Appendix E. Overall, the families describe that most information and education was helpful, easy to understand, pertinent, and recommended for other families. There were mixed responses regarding whether the material enabled families to become more involved and comfortable with their infant's care.

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It is encouraging that the families gave positive remarks regarding the material received. However, additional information and education topics were also identified along with when this knowledge would have benefitted them the most. A detailed list of these topics is presented in Appendix E. Specifically, parents indicated that they preferred information and education to be offered prenatally, on admission, during and after the first week, and when their infant was being transferred. It is compelling to note that families acknowledged a preference to receive a great deal of information during the prenatal period. Interestingly, families also expressed a desire for emotional and administrative support. Finally, all families responded positively to the idea of having a list of the official education available in the NICU.

When asked about preferred delivery methods for information and education in the NICU, most families identified more than one format. Written material, classes, videos, photos, and online formats were identified as being valuable. Families, however, also identified challenges with some of the formats. For example, some families were frustrated that classes were only offered during the day with one family unable to attend because they did not wish to leave their infant's bedside. Additionally, some families were unaware of the opportunities available to them, whereas others felt overwhelmed by the amount of written information provided at any one time. Finally, families provided examples of other formats that would be beneficial, such as face to face discussion, hands on experience, and support from other NICU families or counsellors.

**FHA patient education consultant.** The FHA NICU shared work team and the FHA NICU families are essential resources for this project but an equally important resource is the FHA NICU patient education department. The FHA patient education



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department offers guidance, conducts ongoing evaluations and catalogues FHA patient education. It was important to establish a connection with this department at the beginning of the project. Communication with this department throughout this project aims to ensure the presence of appropriate content, conducive formats, and ensure the development of the FHA NICU family education guide is on target.

***Setting, participants, and methods.*** Telephone contact was initiated with the FHA patient education department. The department directed the call to a FHA patient education consultant who was provided with a brief description of the project's mission, goals, and objectives. The consultant confirmed the previously noted benefits of involving the department in the project and provided verbal consent to participate. Contact details were exchanged and an invitation extended to attend a FHA NICU family education shared work team meeting. The questions guiding discussions with the patient education department at the shared work team meeting can be found in Appendix F.

***Data collection, management, and analysis.*** As previously noted, minutes were written during the meeting with the shared work team and patient education consultant and then distributed via email. A discussion guide was created prior to the meeting, however, all team members contributed to the overall discussion with the consultant. The focus of the first question was for the patient education consultant to provide an overview of their role. Next, the team asked the consultant to provide feedback on the project's mission, goals, and objectives. Finally, questions related to available resources and potential formats were posed. The meeting minutes can be found in Appendix F.

***Results.*** Reflecting upon the meeting with the FHA patient education consultant it is apparent that building a relationship with this department will be very valuable. This

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department offers unique expertise and important contacts. It is reassuring that the mission, goals, and objectives for developing a FHA patient education guide is on target. Ongoing communications will be vital to provide the department with the ability to follow the team's progress. Finally, the patient education consultant also verified that the team accessed all of the available resources within FHA. Other potential sources were also discussed but these would require further assessment and approval therefore the consultant and team decided to develop a list of current, approved resources first prior to exploring resources outside of FHA. It is important to note that ongoing assistance will be needed from the patient education department to help with the assessment of resources that may be required from outside the FHA.

One potential challenge is that currently the FHA patient education department is unable to support publication of online material. The consultant noted, however, that the FHA communication department is responsible for online publication. Given the early stage in the overall development of the family education guide it is too early to tell if and to what extent online publication supports will be necessary. The team has, therefore, decided to delay connecting with the communications department.

### **Summary of the Consultations**

The aforementioned consultations identified specific needs of the target population, FHA NICU families. Consultations with the FHA NICU health care team and FHA NICU families provided the most valuable insight and illustrated that while families are eager to learn they have unique learning needs. The health care team offered information about families' knowledge acquisition whereas the families indicated that it would be very beneficial to ensure education is accessible. Families, however, did

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indicate that the education they received was useful. All of the consultations presented varying ideas regarding education topics. The health care team described frequently asked questions whereas the families pinpointed topics at specific points along their NICU journey. The education consultant, however, verified the locations of education that is currently available to families.

Overall, the consultations verified that family education is required throughout the NICU journey but that it is common for each family to acquire information at different times. The FHA NICU family education guide, therefore, should aim to improve families' accessibility to education currently available as well as offer families with multifaceted learning opportunities. Once complete, the guide will also need to be approved by the FHA patient education department in order to ensure it meets patient education standards.

### **Environmental Scan**

An environmental scan of available education resources within FHA is a necessary prerequisite for developing the FHA NICU family education guide. The patient education consultant also agreed that an environmental scan is an important component of the needs assessment. Tables can be found in Appendix G that illustrate the various sources, formats, languages, and family education topics. Similar to the consultation section, this section will begin with a description of the setting, participants, and methods of the environmental scan. Next, the data collection, management, and analysis will be explained. Then, a detailed description of the results of the environmental scan will be provided as well as a concluding statement regarding the overall assessment of the current available education.

**Setting, participants, and methods.** The two main sources of family education within FHA were reviewed: patient education catalogue and HealthLink BC. The patient education catalogue organizes and manages patient education used by FHA healthcare professionals. This is a public catalogue that can be accessed on the world wide web from a personal computer. A search within the maternal infant child health program was conducted. The HealthLink BC website is a resource for British Columbians, located on the world wide web from a personal computer, that contains credible information on numerous health related topics. A search engine within HealthLink BC was used to pinpoint relevant education. Finally, a list of specific education offered at each FHA NICU, that is not available from the FHA patient education catalogue or HealthLink BC, was compiled. This education was gathered by connecting with the educators of each unit via email and requesting a list of patient education.

**Data collection, management, and analysis.** The criteria used to select relevant resources consisted of any material, in any format, that related to having a baby in the NICU. Excluded from inclusion in this listing were resources focusing on general antepartum, intrapartum, or postpartum topics. A list of the resources retrieved can be found in Appendix G and consists of 54 topics from the patient education catalogue, 79 topics from HealthLink BC, and 25 other topics from the FHA NICUs. All of the material obtained from the catalogue and HealthLink BC were written resources whereas other education offered in FHA NICUs includes a variety of formats such as classes, support groups, photobooks, and videos. Copies of all the written resources were obtained and placed in a FHA patient education binder.

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**Results.** Review of the environmental scan data revealed both the strengths and limitations of the current FHA NICU family education program. The major strength is the abundance of suitable resources. An additional strength is that some of the family education materials are presented in a variety of languages and formats, especially in the tertiary care settings. Conversely, major limitations relate to disorganized resources which are not readily available in the NICUs. For example, the majority of material available requires employees to log onto a computer, browse a list, select appropriate materials, and print the selections. Parents appear to be unaware of, or have limited access to, the wealth of knowledge available to them. Finally, another limitation is that the resources available are not consistent across all FHA NICUs. In general, then, current education within FHA NICUs is inconsistent, disjointed, unavailable, and unit specific. The results of the environmental scan are encouraging as it verifies the need to organize family education in FHA NICUs in order to ensure current education offered to families is consistent and accessible.

### **Discussion**

A needs assessment, including the collection of primary and secondary data, was completed and offers valuable insight into family education programs that can be applied to the planning and development of a FHA NICU family education guide. The discussion attempts to synthesize the knowledge gained from the literature reviews, consultations, and environmental scan. The noted knowledge gaps and other areas requiring improvement will also be highlighted. Lastly, the implications to the development of a FHA NICU family education guide will be described.

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The results of the literature reviews and consultations complement each other. The emotional impact of having an infant in the NICU is apparent and families describe using a range of coping strategies. These responses and subsequent coping methods appear to be unique to each family member. Focus was also placed on the fact that families' needs change throughout the NICU journey with the majority of families indicating that acquiring knowledge and supportive relationships help them cope. These coping methods, however, are not always effective and can be a source of stress. As a result, to combat families' changing needs together with their unique response and coping strategies it was emphasized that programs benefit from being accessible, individualized, and parent directed. Overall, this needs assessment describes that education programs' should aim to encourage families to become more involved with their infant's care as this is expected to help decrease families' stress while also supporting the principles of FCC.

The literature reviews and consultations encompass a wide variety of knowledge but gaps remain in our understandings. Upon appraisal of the literature the design and quality of the available research is good since only four of the 33 articles were rated with weak design and low quality. However, the application of theory within the research was limited and lessens the quality of the evidence. There is an abundance of literature on NICU family needs and experiences but literature on NICU family education programs is limited. The literature available on education programs covered a wide range of topics but further research about the effectiveness of specific program features would be valuable. For example, research regarding the benefits of particular education delivery methods, topics, scheduling, or the application of web 2.0 technology would further the success of education programs. Furthermore, fewer case reports and more randomized controlled

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trials about education programs would be beneficial and strengthen the evidence.

Additional evidence regarding the impact of education programs would also heighten awareness and enhance support for the development of comprehensive education programs. Future research that focuses on how to incorporate FCC into all areas of NICU practice, including education, would also be beneficial. Finally, both the literature and consultations identified the need to ensure education is accessible but there is limited information about how this can be accomplished other than the use of multiple delivery methods.

The consultations did present valuable insight but there are noted areas of improvement. The focus of the consultations was very specific and they only explored families' educational experiences, whereas the literature describes all aspects of the families' experience. Also, further exploration on the features that make each delivery method effective would further planners ability to assess current education. Lastly, further examination of effective aspects of program implementation would be beneficial to the development and implementation of the FHA NICU family education guide.

Acknowledgement of the knowledge gaps and potential areas of improvement is important but the implications of this needs assessment towards the development of the FHA NICU family education guide can be explored. EBP is verified as fundamental therefore, incorporation of EBP will occur throughout program development, such as applying EBP during the selection of appropriate content and format. For example, suggestions of delivery methods and the education required at different points on the NICU journey are offered within this needs assessment. Also, continued consultation

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during development with families and the health care team will help to ensure that the program's content is appropriate.

This project also benefits from the knowledge gained about the implementation strategies suggested in the literature. The inclusion of families and the multidisciplinary team during implementation is important as this will help to ensure families' needs and principles of FCC are supported. Similarly, ensuring the FCC approach is integrated into all aspects of the education program will be an extremely valuable component. Once the guide is created, obtaining feedback from NICU HCPs and NICU families using the program will also help to identify any unforeseen challenges. It is expected that members of the FHA NICU family education shared work team will assist with implementation but further delineation of the many roles required will need to occur prior to implementation. Finally, completion of the environmental scan supports the need for the development of a family education guide. It is encouraging that there is an abundance of education currently available to families in a variety of topics and formats. The education guide's main priority will be to ensure that current written education is more accessible. As families' needs are unique and constantly changing there are many benefits to increasing the accessibility of current education. Families will have access to the information when they need it with applicable education topics suggested within each step in the NICU journey. Improving accessibility will also support families' ability to individualize their learning and promotes a parent directed approach. In addition, increasing the accessibility of education will help to ensure that consistent information is offered throughout FHA. Providing families with access to consistent, reliable information, therefore, aims to help



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families cope with the stress of having an infant in the NICU and fosters parents' attainment of a parental role.

### Conclusion

Gathering evidence that supports and informs the development of a FHA NICU family education guide was the focus of this needs assessment. The literature reviews and consultations that were conducted complemented each other and aided in gaining a greater understanding of families' needs as well as elucidates many aspects of family education. Moreover, consultation with the FHA NICU family education shared work team and patient education consultant will be ongoing and offer further support to this project. Finally, the environmental scan of FHA NICU family education offers a solid foundation to build upon in this effort to create a valuable resource for families and tool for HCPs. Overall, this needs assessment supports the following mission of this proposed endeavor; restructure the FHA NICU family education to meet the needs of NICU families throughout their NICU journey and support the principles of family centered care.

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## Appendix A

## Evidence Summary Tables

Table A1

## Qualitative Research of NICU Parents' Experiences and Informational Needs

Name, Author, Date, Study Objective	Design	Theoretical Background	Key Findings	Strengths/ Limitations	Overall Rating
Experiences of Fathering a Baby Admitted to Neonatal Intensive Care: A Critical Gender Analysis, Deeney, K., Lohan, M., Spence, D., Parkes, J. (2012). Gain a greater understanding of the experiences of fathers in the NICU.	- Qualitative, longitudinal, descriptive design - 21 fathers in a NICU in Northern Ireland.	- Feminist critical studies on men.	- Reviews the impact of the NICU environment. - Identified that NICU fathers have unique challenges. - Fathers' challenges relate to the female dominance within the NICU and archaic perspectives that men are providers and females are caregivers. - Fathers have difficulties attaining a parental role in the NICU.	<b>Strengths:</b> - Well defined research question. - Purposive sampling with good description of sampling strategy. - Data collection complete and methodology appropriate with justification. - Ethical approval and consent obtained. <b>Limitations:</b> - None	<b>Strong</b> study design with <b>high</b> quality that utilizes direct evidence with implications to nursing practice.
The lived experiences of	- Qualitative, descriptive	-Analysis based upon	- Five themes emerged from the interviews:	<b>Strengths:</b> - Well defined	<b>Strong</b> study design with <b>high</b>

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<p>fathers of a premature baby on a neonatal intensive care unit, Hollywood, M. &amp; Hollywood, E. (2011). Describe the experiences of fathers in the NICU.</p>	<p>phenomenological design. - 5 fathers in a tertiary care level NICU in Dublin, Ireland. - Face to face interviews.</p>	<p>phenomenological inquiry.</p>	<p>Effects of hospitalization (anxiety and helplessness), realization of becoming a father too soon, information sharing (positive and negative effects), parental role compared to maternal role, limitations of work.</p>	<p>research question. - Complete data collection with appropriate methodology and justification. - Ethics approval and consent obtained. <b>Limitations:</b> - Purposive sampling with description of sample criteria but poor rationale for sample size.</p>	<p>quality that utilizes direct evidence with implications to nursing practice.</p>
<p>From Distance Toward Proximity: Fathers' Lived Experience of Caring for Their Preterm Infants, Lundqvist, P., Wetås, L.H., &amp; Hallström, I. (2007). Examine and describe fathers' experience of having an infant in the NICU.</p>	<p>- Qualitative, descriptive, longitudinal, hermeneutic, phenomenological design - 14 fathers from a 10-bed, level 2 NICU in Sweden - Interviews, that lasted 45-60 minutes, 1-3 months after discharge.</p>	<p>- Inductive hermeneutic phenomenological approach. - Research aim was founded on principles of FCC.</p>	<p>- Fathers' experience in the NICU is a progression of Feelings of Distance (Living beside reality, becoming an outsider, living with worry) to Feelings of Proximity (returning to reality, becoming a family, and facing the future). - Specific feelings that were identified in feelings of distance are: range of emotions,</p>	<p><b>Strengths:</b> - Well defined research question. - Convenience sampling with description of sampling criteria. - Data collection and analysis appropriate and thorough with justification. - Ethical approval and consent obtained.</p>	<p><b>Strong</b> study design with <b>high</b> quality that utilizes direct evidence with implications to nursing practice.</p>

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			<p>surrealness, negative influence of NICU environment, range of responsibilities, lack of control, barriers to attaining a parental role</p> <ul style="list-style-type: none"> <li>- Specific feelings identified in toward a feeling of proximity: realism, motivated, attain a parental role, new responsibilities.</li> <li>- Suggested when to provide specific information and what information to provide.</li> </ul>	<p><b>Limitations:</b></p> <ul style="list-style-type: none"> <li>- Lack of ethnic diversity.</li> </ul>	
<p>A Qualitative Study of Parents' Perspectives on Neonatal Intensive Care at the Extremes of Prematurity, Pepper, D., Rempel, G., Austin, W., Ceci, C., &amp; Hendson, L. (2012). A description of NICU parents' perceptions and decision making</p>	<ul style="list-style-type: none"> <li>- Qualitative, interpretive, approach.</li> <li>- 5 Semi structured interviews and demographic data collected from a total of 7 parents that represented 5 families (recruited from a tertiary care western Canadian NICU).</li> </ul>	<ul style="list-style-type: none"> <li>- Followed research principles by Morse and Field.</li> <li>- Identified that the mission statement within this western Canadian NICU supports family-centered care.</li> </ul>	<ul style="list-style-type: none"> <li>- Identified 2 themes: decision making before and in the NICU (moving beyond information), culture shock in the NICU (plunging into a strange land), relationships in the NICU (enduring in a strange land).</li> <li>- Described that influences of parental decision making in the NICU include parental values and beliefs,</li> </ul>	<p><b>Strengths:</b></p> <ul style="list-style-type: none"> <li>- Well defined research question.</li> <li>- Sampling criteria and strategy described.</li> <li>- 50% of sample participated</li> <li>- Data collection and analysis techniques described in detail and assessed to be strong and</li> </ul>	<p><b>Strong</b> study design with <b>high</b> quality that utilizes direct evidence with implications to nursing practice.</p>

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process.			environment, information, language, and the development of relationships.	appropriate and justified. - Ethics approval and consent obtained. <b>Limitations:</b> - None.	
Mothers' experiences of Having their Newborn Child in a Neonatal Intensive Care Unit, Wigert, H., Johansson, R., Berg, M., & Hellstrom, A.L. (2006). Gain a greater understanding of mothers' experiences in the NICU.	- Qualitative, interpretive, phenomenological hermeneutic design. - 10 mothers with term babies in a NICU in Sweden. - Face to face, open ended interviews.	-Hermenutic	- Mothers expressed fluctuating feelings from exclusion to involvement. - Three themes emerged: feeling of interaction, feeling of belonging or not belonging, maternal feelings.	<b>Strengths:</b> - Well defined research question. - Sampling criteria described - Data collection complete and analysis appropriate with justification. - 4 researchers performed analysis. - Ethical approval and consent obtained. <b>Limitations:</b> - Poor description of sampling strategy.	<b>Strong</b> study design with <b>high</b> quality that utilizes direct evidence with implications to nursing practice.
Parents' Perceptions Regarding Readiness for their Infant's Discharge	- Qualitative, descriptive approach. - 20 parents from a	-None stated	- Four main themes emerged: informational needs (about routine care and unexpected events),	<b>Strengths:</b> - Well defined research question. - Sampling	<b>Strong</b> study design with <b>high</b> quality that utilizes direct

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from the NICU, Burnham, N., Feeley, N., & Sherrand, K. (2013). Evaluates parents' perceptions of what information they require upon discharge; who should provide this education, the preferred format and when they want to receive this education.	tertiary level NICU in Quebec, Canada: 10 parents pre-discharge and 10 parents post-discharge. - Face to face, semistructured interviews and demographic data collection.		hands-on experience, cues from the infant and from the NICU environment, tailoring to infant/family situation. - Describes specific information and formats that parents viewed as important. - Emphasizes the importance of an individualized education plan.	criteria and strategy described. - Data collection and analysis techniques described in detail and assessed to be strong and appropriate with justification provided. - Ethics approval and consent obtained. <b>Limitations:</b> - Lack of input from fathers. - Lack of variety in sample with regards to acuity of infant or parents that do not visit regularly.	evidence with implications to nursing practice.
Mothers' Experiences of Having a Preterm Infant in the Neonatal Care Unit: A Meta-Synthesis, Aagaard, H. & Hall,	- Systematic review, metasynthesis - 14 Qualitative studies, published from 2000 onward	- Noblit and Hare's meta-ethnographic approach	- Two groups of studies reviewed: mothering of preterm infants and mothering of preterm and full term infants - Five themes were identified: mother-baby	<b>Strengths:</b> - Well defined research question. - Appropriate methodology with justification. - Inclusion	<b>Strong</b> study design and <b>medium quality</b> literature review that applies methodology appropriately and

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E.O.C. (2008). Explore the literature to describe mothers' NICU experiences.			relationship: from their baby to my baby; maternal development: a striving to be a real normal mother; maternal caregiving and role reclaiming strategies: from silent vigilance to advocacy; mother-nurse relationship: from continuously answering questions through chatting to sharing of knowledge	criteria clearly stated and relevant. - Comprehensive search of multiple databases. - Included discussion of each study. - Identified relevant and appropriate relationships. - Results can be applied to similar settings. <b>Limitations:</b> - Limited variety of study methodologies available. - Poor description of the quality of the studies used.	includes implications to nursing practice but as critical appraisal of articles not described it is difficult to identify the quality of the evidence.
Fathers' Experiences in the Neonatal Intensive Care Unit: A Search for Control, Arockiasamy, V., Holsti, L., &	- Qualitative, descriptive content analysis design. - 16 fathers in a tertiary care NICU in Vancouver, British Columbia,	- None specified	- Central theme of lack of control. - Five subthemes include: Values and belief systems, information, communication, roles,	<b>Strengths:</b> - Well defined research question. - Purposive sampling until data saturation occurred.	<b>Moderate</b> study design with <b>medium</b> quality that utilizes direct evidence with implications to nursing practice

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Albersheim, S. (2008). Gain a greater understanding of the experiences of fathers in the NICU.	Canada. - Semi-structured interviews with open-ended questions.		external activities. - Important relationships include: spouses, family and friends, HCPs. - Preferred methods for delivery of information described. - Individualization of care important.	- Data collection complete and methodology appropriate (constant comparative analysis). - Ethical approval and consent obtained. <b>Limitations:</b> - Poor justification of methodology or specification of theoretical background.	but does not describe specific theoretical background to support methodology.
Parenting in the Neonatal Intensive Care Unit, Cleveland, L.M. (2008). Explored the literature to explore NICU parent needs and supportive nursing behaviours.	- Systematic literature review. - 60 studies reviewed, including both quantitative and qualitative research (19 focused on parenting needs, 24 supportive behaviours, 17 both). - Conventional content analysis.	- Relates to family centered care and does identify the role of family centered care in the NICU.	- Six needs of NICU parents noted in the literature: provided with correct information and involvement in their infant's care and decision making, protective and presence in the NICU, interacting with their infant, considered to be an important and beneficial by the HCPs, personalized care,	<b>Strengths:</b> - Well defined research question. - Inclusion criteria specified and appropriate. - Comprehensive literature search described. - Analysis of literature resembles similar studies. - NICU focus,	<b>Moderate</b> study design with <b>medium</b> quality that utilizes direct evidence with implications to nursing practice but has some limitations with regards to methodology and does not describe specific theoretical

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			<p>supportive and caring relationship with nurses.</p> <ul style="list-style-type: none"> <li>- Four supportive behaviours noted in the literature: emotional support, empowering parents, inviting environment that has complementary unit policies, provision of education that includes hands-on experience.</li> </ul>	<p>therefore, results applicable.</p> <p><b>Limitations:</b></p> <ul style="list-style-type: none"> <li>- Only 1 reviewer noted.</li> <li>- No theoretical background identified.</li> <li>- Poor description of the quality of the studies used.</li> <li>- Limited evidence for different cultures.</li> </ul>	<p>background to support methodology.</p>
<p>Parental Perceptions in Neonatal Care, Gavey, J. (2007). Explore the experience of NICU parents.</p>	<ul style="list-style-type: none"> <li>- Qualitative, descriptive design.</li> <li>- 16 NICU parents from a tertiary care NIUC in the UK.</li> <li>- Interviews.</li> </ul>	<p>-None noted</p>	<ul style="list-style-type: none"> <li>- The themes that emerged from the interviews include: preparation for delivery, parental impression of the NICU, care delivery throughout maternal and neonatal hospitalization, the impact the NICU had on relationships, and professional control versus perceived lack of parental control.</li> <li>- Only two of these themes were discussed in this article: parental impressions and care</li> </ul>	<p><b>Strengths:</b></p> <ul style="list-style-type: none"> <li>- Well defined research question.</li> <li>- Appropriate methodology.</li> <li>- Description of data collection and analysis appropriate.</li> <li>- Ethical approval and consent obtained.</li> </ul> <p><b>Limitations:</b></p> <ul style="list-style-type: none"> <li>- Poor justification of methodology.</li> <li>- Convenience</li> </ul>	<p><b>Moderate</b> study design with <b>medium</b> quality that utilizes direct evidence with implications to nursing practice but fails to justify use of methodology and sample size.</p>



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			<p>delivery.</p> <ul style="list-style-type: none"> <li>- Describes the benefits of journaling for NICU parents.</li> <li>- Specifies that communication and building trusting relationships with HCPs is important.</li> </ul>	<p>sampling and criteria described but poor rationale for sample size.</p> <ul style="list-style-type: none"> <li>- More mothers than fathers were interviewed.</li> </ul>	
<p>Factors Affecting Parents' Presence with their Extremely Preterm Infants in a Neonatal Intensive Care Room, Heinemann, A., Hellstrom-Westas, L., Hedberg-Nyqvist, K. (2013). Examine influences that encourage and discourage NICU parents' visitation.</p>	<ul style="list-style-type: none"> <li>- Qualitative, descriptive approach.</li> <li>- 7 mothers and 6 fathers from a tertiary level NICU in Sweden.</li> <li>- Face to face, semistructured interviews with the use of a conversation guide.</li> </ul>	<ul style="list-style-type: none"> <li>- The kangaroo mother care method directed the interviews and conversation guide.</li> </ul>	<ul style="list-style-type: none"> <li>- Identified 2 major themes: coping with a new and unexpected situation (handling the situation, emotions and reactions, being with the infants, experiences and impressions of the environment) and becoming a parent (interaction and communication with HCP, growing into the parent role, interaction with the infant)</li> <li>- Results support family-centered care approach and includes practical information about how to provide family-centered care in the NICU.</li> </ul>	<p><b>Strengths:</b></p> <ul style="list-style-type: none"> <li>- Well defined research question.</li> <li>- Sample description provided.</li> <li>- Data collection and analysis techniques described in detail and assessed to be strong and appropriate.</li> <li>- Ethics approval obtained.</li> </ul> <p><b>Limitations:</b></p> <ul style="list-style-type: none"> <li>- Sample criteria and strategy not described.</li> <li>- Poor justification of methodology and</li> </ul>	<p><b>Moderate</b> study with <b>medium</b> quality that utilizes direct evidence with implications to nursing practice.</p>

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				no specification of theoretical background.	
Coping with the NICU experience: Parents' Strategies and Views of Staff Support, Smith, V.C., SteelFisher, G.K., Salhi, C., & Shen, L.Y. (2012). Assess NICU parent experiences, coping strategies, and NICU staff support.	<ul style="list-style-type: none"> <li>- Qualitative design.</li> <li>- Face to face semi-structured interviews and demographics with 24 families from a 40-bed tertiary care NICU in Boston.</li> </ul>	<ul style="list-style-type: none"> <li>- Limited application of grounded theory.</li> </ul>	<ul style="list-style-type: none"> <li>- Identified 5 parent coping strategies: participation in care, getting away from the NICU, gathering information, involvement of friends and family, engagement with other NICU families.</li> <li>- Identifies that families benefit from journaling, receiving consistent and regular information, and an individualized approach.</li> </ul>	<b>Strengths:</b> <ul style="list-style-type: none"> <li>- Well defined research question.</li> <li>- Multiple recruitment strategies described and sampling criteria described.</li> <li>- 69% response rate.</li> <li>- Data collection and analysis techniques described in detail and assessed to be strong and appropriate with justification (Applied aspects of grounded theory, including constant comparative analysis)</li> <li>- Ethics approval and consent obtained.</li> </ul>	<b>Moderate</b> study design with <b>medium</b> quality that utilizes direct evidence with implications to nursing practice but does not describe sampling strategy, validity, or reliability of interview tool.

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				<b>Limitations:</b> - Sampling strategy not described. - Did not discuss validity or reliability of interview tool.	
Hope, Disclosure, and Control in the Neonatal Intensive Care Unit, Charchuk, M. & Simpson, C. (2005). Discussion about a NICU parent's perspective on the relationship between hope, communication, and control.	- Qualitative, case report. - Experience of 1 mother in a tertiary care NICU.	-None specified.	- Provides definition of hope as it relates to NICU parents - Discusses what interactions maintain hope as having hope helps relieve stress. - Lack of communication can create feelings of hopelessness and concern. - Discusses that the NICU environment and NICU activities creates lack of control, isolation, lack of trust, exclusion, decreases ability to assume parental role. - Cannot assume parents' do not want to be informed through their actions. HCP should	<b>Strenghts:</b> - Well defined purpose. - Discusses NICU experience. - Applied results of literature review to discussion content. <b>Limitations:</b> - Self- description of the NICU experience with very specific topic explored.	<b>Weak</b> study design with <b>medium relevancy.</b> Detailed discussion of NICU experience that utilized evidence to support statements but it is a self-report with a very specific focus.

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			offer parents the truth to ensure trust is established.		
Information Needs of Parent of Children Admitted to a Neonatal Intensive Care Unit: A Review of the Literature (1990-2008). De Rouck, S. & Leys, M. (2009). A review of the literature to gain a greater understanding of NICU parents' information and communication needs at different stages during the NICU stay.	<ul style="list-style-type: none"> <li>- Narrative literature review.</li> <li>- 78 articles included, limited to 1990-2008 English articles, and includes both quantitative and qualitative research.</li> </ul>	- None specified.	<ul style="list-style-type: none"> <li>- Discussion of literature divided into various categories: information and communication, information sources, trajectory and phases, timing of information, and communication style.</li> <li>- Described that information and communication is needed in order to gain control, engage, adapt, and cope.</li> <li>- Described the variety of information sources and delivery methods.</li> <li>- Described the NICU journey and various phases within the NICU journey.</li> <li>- Described the unique needs of each family, therefore, individualized care plans needed as well as the need for information to be repeated and reinforced.</li> </ul>	<p><b>Strengths:</b></p> <ul style="list-style-type: none"> <li>- Focused and relevant research purpose.</li> <li>- Inclusion criteria included, detailed description of included studies provided.</li> <li>- Comprehensive literature search using multiple databases.</li> <li>- Literature retrieved focused on the NICU population.</li> </ul> <p><b>Limitations:</b></p> <ul style="list-style-type: none"> <li>- Not a metasynthesis.</li> <li>- No description of the critical appraisal of the literature.</li> <li>- Use of only 1 reviewer.</li> </ul>	<p><b>Weak</b> study design with <b>low</b> quality as despite reviewing 78 articles, only 1 researcher was used and no details regarding the critical analysis of the studies was included. Unable to determine the quality of the literature used.</p>

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			- Described the importance of specific communication styles.		
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**Table A2**

## Quantitative and Mixed Methods Research of NICU Parents' Experiences and Informational Needs

Jordanian Parental Needs of Critically Infants in Neonatal Intensive Care Units, Obeisat, S.M. & Hweidi, I.M. (2014). Investigate NICU parents view of their needs.	- Quantitative, descriptive, correlational design. - 170 NICU parents in 3 hospitals in northern Jordan. - Arabic version of the NICU Family Needs Inventory (NFNI), a 56 questions using a 4-point Likert scale and demographic data.	None stated	- Parents viewed the following five needs as the highest: To feel that hospital personnel care about my infant, To have question about my infant answered honestly, To know the expected outcomes for my infant, To receive more information about the condition of my infant at least once a day, To be assured that best care possible is being given to my infant. - The top ten responses were associated with: Assurance, information, proximity, and comfort.	<b>Strengths:</b> - Well defined research question. - 85% response rate. - Appropriate data collection techniques. - NFNI survey is reliable and credible (Cronbach $\alpha$ 0.90). - Ethical approval and consent obtained. - Appropriate use of statistics. <b>Limitations:</b> - Convenience sampling.	<b>Weak</b> study design with <b>high</b> quality that utilizes direct evidence with implications to nursing practice.
Family Centered care?	- Quantitative,	- FCC	- Outlines the various	<b>Strengths:</b>	<b>Weak</b> study

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<p>Facilities, information and support for parents in UK neonatal units, Redshaw, M.E., Hamilton, K.E.StC. (2010). Examine how UK NICUs assist the communication, support, and education needs of NICU families.</p>	<p>descriptive, cross-sectional design. - All UK NICU managers invited to participate. - On-line survey.</p>	<p>discussed in relation to the results.</p>	<p>NICU designs, policies, and educational topics and formats. - There is a great deal of variances amid all the UK NICUs. - The variances did not seem to relate to the acuity of the NICUs.</p>	<p>- Well defined research question. - Use of multiple recruitment strategies. - 72% response rate. - Ethics approval not applicable. - Appropriate use of descriptive statistics significance level identified. - Use of literature to support background discussion. <b>Limitations:</b> - Only took place in UK, therefore, results may not be applicable to other countries. - No information on validity or reliability of survey.</p>	<p>design with <b>high</b> quality study that utilizes direct evidence with implications to nursing practice.</p>
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<p>Identification of Parental Stressors in an Australian Neonatal Intensive Care Unit, Sweet, L. &amp; Mannix, T. (2012). Explores the types and amount of NICU parental stress.</p>	<ul style="list-style-type: none"> <li>- Mixed methods, descriptive design.</li> <li>- 40 parents (24 mothers and 16 fathers), in a tertiary NICU in Southern Australia.</li> <li>- Use of 3 surveys: Parental Stressor Scale: NICU (PSS:NICU), Critical Care Maternal Needs Inventory, Neonatal therapeutic intervention scoring system (NTSS).</li> </ul>	<p>-None specified</p>	<ul style="list-style-type: none"> <li>- Themes identified included: separation, communication, comprehension, HCP mannerisms, empathy</li> <li>- Highlights NICU stressors. The highest stressor was alteration in parental role followed by infant appearance.</li> <li>- Highest needs were associated with communication and information.</li> <li>- Identifies effective HCP practices: communication, access, information, assurance, educational-behavioural intervention program.</li> </ul>	<p><b>Strengths:</b></p> <ul style="list-style-type: none"> <li>- Well defined research question.</li> <li>- Data complete and analysis appropriate. Use of descriptive statistics and thematic analysis.</li> <li>- Ethical approval and consent obtained.</li> </ul> <p><b>Limitations:</b></p> <ul style="list-style-type: none"> <li>- Convenience sampling.</li> <li>- Data only collected in 1 unit.</li> </ul>	<p><b>Weak</b> study design with <b>high</b> quality that utilizes direct evidence with implications to nursing practice.</p>
<p>Effect of Nursing Interventions on Stressors of Parents of Premature Infants in Neonatal Intensive Care Unit, Turan, T., Basbakkal, Z., &amp; Ozbek, S. (2008). Identifying nursing interventions that reduce NICU parents' stress.</p>	<ul style="list-style-type: none"> <li>- Quantitative, descriptive design.</li> <li>- 40 NICU parents in a 15-bed NICU in Denizli, Turkey.</li> <li>- Trait anxiety inventory (STAI: 40 question tool), Parental stress scale (PSS): NICU, and demographic data.</li> </ul>	<p>- Family centered care discussed.</p>	<ul style="list-style-type: none"> <li>- Demonstrates that parents experience less stress when provided with support and information.</li> <li>- Discussed sources of stress in the NICU: unfamiliar and intimidating environment; difficulties assuming parental roles</li> </ul>	<p><b>Strengths:</b></p> <ul style="list-style-type: none"> <li>- Well defined research question.</li> <li>- Randomization to control or intervention group.</li> <li>- Data collection complete and analysis appropriate.</li> </ul>	<p><b>Weak</b> study design with <b>high</b> quality that utilizes direct evidence with implications to nursing practice.</p>

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			(due to unexpected ways to assume parental role).	<ul style="list-style-type: none"> <li>- Surveys credible (STAI has Cronbach <math>\alpha</math> of 0.83 and PSS:NICU has Cronbach <math>\alpha</math> of 0.73-0.92).</li> <li>- Ethics approvals and consent obtained.</li> </ul> <p><b>Limitations:</b></p> <ul style="list-style-type: none"> <li>- Small sample.</li> <li>- Data only conducted in 1 setting.</li> </ul>	
<p>Assessment of Family Needs in Neonatal Intensive Care Units, Mundy, C.A. (2010). Assess needs of NICU parents using a reliable and standard tool.</p>	<ul style="list-style-type: none"> <li>- Quantitative, descriptive, correlational design.</li> <li>- 60 NICU parents from a tertiary care NICU in Georgia.</li> <li>- Face to face interviews using the NICU Family Needs Inventory (NFNI) tool.</li> </ul>	<ul style="list-style-type: none"> <li>- Description of purpose, results, and implications illustrate apparent association to family centered care approach.</li> </ul>	<ul style="list-style-type: none"> <li>- Identified most important and least important NICU family needs.</li> <li>- Most important needs are: notified of changes to infant condition; assurance; empathetic, gentle, and honest care givers; rationale for medical decisions and care; receive hope; open visitation; identification of infant's progress; expected outcomes of infant; be involved with</li> </ul>	<p><b>Strengths:</b></p> <ul style="list-style-type: none"> <li>- Well defined research question</li> <li>- 97% participation.</li> <li>- Data collection and analysis techniques described in detail and assessed to be strong and appropriate.</li> <li>- Described the validity and reliability of the NFNI (Cronbach</li> </ul>	<p><b>Weak</b> study design with <b>medium</b> quality that utilizes direct evidence with implications to nursing practice.</p>



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			<p>infant's care.</p> <ul style="list-style-type: none"> <li>- Provides further validation for the NFNI.</li> <li>- Each family and subsequently each family member is unique; each family is aware of their needs and not health care professionals</li> </ul>	<p>α 0.94).</p> <ul style="list-style-type: none"> <li>- Ethics approval obtained.</li> </ul> <p><b>Limitations:</b></p> <ul style="list-style-type: none"> <li>- Convenience sampling.</li> <li>- Small sample with infants of variable acuity and from only 1 setting.</li> <li>- Only parents were included, not other family members.</li> </ul>	
<p>Identification of Internal and External Stressors in Parents of Newborn in Intensive Care, Grosik, C., Synder, D., Cleary, G.M., Breckenridge, D.M., &amp; Tidwell, B. (2013). Examines parents' perception of stress in the NICU, including internal and external stressors.</p>	<ul style="list-style-type: none"> <li>- Quantitative, descriptive, cross-sectional design.</li> <li>- 119 participants from a tertiary level, 28-bed NICU in Philadelphia, USA.</li> <li>- 4 questionnaires: Internal stressor questionnaire (PSS:NICU) (Likert scale), External stressors and stress reduction scale questionnaire</li> </ul>	<ul style="list-style-type: none"> <li>- Neuman's conceptual framework.</li> <li>- Discusses the relevance of FCC in the NICU setting.</li> </ul>	<ul style="list-style-type: none"> <li>- Identifies that a NICU admission is defined as 'traumatic'.</li> <li>- High stress scores were related to parents observations of their baby's stress or critically ill, NICU environmental factors, separation, helplessness, responsibilities outside of the hospital setting.</li> <li>- Stress reducing techniques include family and friend supports and other NICU</li> </ul>	<p><b>Strengths:</b></p> <ul style="list-style-type: none"> <li>- Well defined research question</li> <li>- Ethics approval obtained.</li> <li>- Appropriate use of descriptive statistics.</li> <li>- Use of literature review to provide background to topic.</li> </ul> <p><b>Limitations:</b></p> <ul style="list-style-type: none"> <li>- Convenience sample with inclusion criterial</li> </ul>	<p><b>Weak</b> study design with <b>low</b> quality that that utilizes direct evidence but poor description of methodology therefore appraised study with low quality.</p>

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	(Likert scale), Demographic data		families. - Discusses a NICU parent scrapbooking activity to promote relationships with other NICU families.	specified. - No indication of data collection specifics or missing data. - No information on survey credibility. - Not generalizable as only took place in 1 setting.	
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**Table A3**

### Quantitative Research of NICU Education Programs

<b>Name, Author, Date, Study Objective</b>	<b>Design</b>	<b>Theoretical Background</b>	<b>Key Findings</b>	<b>Strengths/ Limitations</b>	<b>Overall Rating</b>
Impacts of Creating Opportunities for Parent Empowerment on Maternal Stress: A Quasi-experimental Study, Borimnejad, L., Mehrnoosh, N., Fatemi, N.S., & Haghani, H. (2013).	- Analytical, randomized control design. - 140 mothers of preterm infants in 2 NICUs in Iran. - Parental Stressor Scale Survey	- The COPE program provides a family centered care approach	- Baseline stress levels were the same for both groups. Stress levels were significantly lower in the intervention group compared to the control group. - Highest levels of stress were due to: infant appearance and behaviour,	<b>Strengths:</b> - Well defined research question. - 100% response rate. - High survey reliability and validity. - Consent obtained.	<b>Strong study:</b> <b>High</b> quality with direct evidence.

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Assess the impact of the Creating Opportunities for Parent Empowerment (COPE) program on NICU mothers' stress levels.			parental roles and their association with neonates, and NICU environment.	<ul style="list-style-type: none"> <li>- Data collection and analysis are appropriate.</li> <li>- 95% confidence interval and 80% study power, with 20% missing data.</li> </ul> <p><b>Limitations:</b></p> <ul style="list-style-type: none"> <li>- Volunteer participant selection.</li> </ul>	
Reducing Premature Infants' Length of Stay and Improving Parents' Mental Health Outcomes with the Creating Opportunities for Parent Empowerment (COPE) Neonatal Intensive Care Unit Program: A Randomized, Controlled Trial, Melnyk, B.M., Feinstein, N.F., Alpert-Gillis, L., Fairbanks, e., Crean, H.F., Sinkin, R.A., Stone, P.W.,	<ul style="list-style-type: none"> <li>- RCT.</li> <li>- 245 mother, 145 fathers, and 247 infants.</li> <li>- 2 tertiary care NICUs in New York State (52 bed and 60 bed).</li> <li>- Measured length of stay (LOS).</li> <li>- State-Trait Anxiety Inventory (20-items)</li> <li>- Beck Depression Inventory.</li> <li>- Parental Stressor Scale-Neonatal Intensive Care (PSS-NICU) (46-item using 5-point</li> </ul>	<ul style="list-style-type: none"> <li>- Self-regulation and Control theories.</li> </ul>	<ul style="list-style-type: none"> <li>- The impact of an educational-behavioral intervention program early in the NICU stay results in the following outcomes: decrease in maternal stress, anxiety and, depressive symptoms, stronger parental beliefs, increase in positive parent-infant interactions, decrease LOS.</li> <li>- Describes content of a 4-phase educational-behavioral intervention program (COPE).</li> </ul>	<p><b>Strengths:</b></p> <ul style="list-style-type: none"> <li>- Well defined research question.</li> <li>- Specified recruitment criteria from 2 settings.</li> <li>- Random sampling.</li> <li>- 96% response rate.</li> <li>- Strong internal validity for all tools</li> <li>- 87% participants completed study.</li> <li>- Ethical approval and consent obtained.</li> <li>- Strong data</li> </ul>	<p><b>Strong study:</b></p> <p><b>High</b> quality that utilizes direct evidence.</p>

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Small, L., Gross, S.J. (2006). Examine the impact of the COPE, an educational-behavioral intervention program.	<p>Likert scale)</p> <ul style="list-style-type: none"> <li>- Index of Parental Behaviour in the NICU (15-item)</li> <li>- Parental Belief Scale-NICU (18-item, 5-point Likert scale)</li> <li>- Clinical Risk Index for Babies (CRIB)</li> </ul>			<p>analysis.</p> <p><b>Limitations:</b></p> <ul style="list-style-type: none"> <li>- Research only conducted in 2 settings.</li> <li>- Only assessed short term outcomes.</li> </ul>	
Translating the Evidence-Based NICU COPE Program for Parents of Premature Infants Into Clinical Practice: Impact on Nurses' Evidence-Based Practice and Lessons Learned, Melnyk, B.M., Bullock, T., McGrath, J., Jacobson, D., Kelly, s., & Baba, L. (2010). Assess nurses' beliefs after implementation of the evidence-based COPE program,	<ul style="list-style-type: none"> <li>- Cohort, analytic study</li> <li>- 81 nurses from a NICU in the Southwest region of the US participated.</li> <li>- 2 Surveys: evidence-based practice beliefs scale (5 point Likert scale) &amp; evidence-based practice implementation scale (5 point Likert scale).</li> </ul>	- Evidence-based practice.	<ul style="list-style-type: none"> <li>- Evidence-based practice beliefs were significantly higher after the COPE program was implemented.</li> <li>- No significant change in evidence-based implementation between the two groups.</li> <li>- Description of the impact of an evidence-based practice mentor to assist with implementation.</li> </ul>	<p><b>Strengths:</b></p> <ul style="list-style-type: none"> <li>- Well defined research question.</li> <li>- Data collection and data analysis appropriate, valid, and reliable (surveys had high validity).</li> </ul> <p><b>Limitations:</b></p> <ul style="list-style-type: none"> <li>- Required volunteer participants.</li> <li>- 45% response rate.</li> <li>- No evidence of ethics approval or consent.</li> <li>- Poor controls of confounding</li> </ul>	<b>Medium study:</b> medium quality with direct evidence

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evaluate the implementation plan of the COPE program, and identification of the strengths and limitations of implementing the COPE program.				variables.	
Nurse-led Education Mitigates Maternal Stress and Enhances Knowledge in the NICU, Morey, J.A. & Gregory, K. (2012). Examines how educational intervention for high-risk pregnant women in the prenatal period impacts maternal stress.	<ul style="list-style-type: none"> <li>- Quantitative, analytical, adequate, interrupted time series design.</li> <li>- 42 high risk hospitalized pregnant women in the North Eastern United States.</li> <li>- Parental Stressor Scale: NICU (PSS:NICU), a 26 question, 5-point Likert scale plus 4 additional (pilot tested) questions about the educational intervention class</li> <li>- Demographic data also collected.</li> </ul>	- None specified	<ul style="list-style-type: none"> <li>- Results indicate that education provided to high-risk pregnant women in the prenatal period decreases maternal stress.</li> <li>- Describes the content of the prenatal education program.</li> </ul>	<b>Strengths:</b> <ul style="list-style-type: none"> <li>- Moderate study design.</li> <li>- Well defined research question.</li> <li>- 100% participation.</li> <li>- No missing data noted.</li> <li>- Information bias controlled.</li> <li>- Valid and reliable survey tool (Cronbach <math>\alpha</math> = 0.89)</li> <li>- 76% participants completed all aspects of the study.</li> <li>- Ethics approval and consent obtained.</li> </ul>	<b>Medium study:</b> Medium quality that utilizes direct evidence with implications to nursing practice.

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				<ul style="list-style-type: none"> <li>- Appropriate statistical analysis (RM-ANOVA) with adequate sample size.</li> </ul> <p><b>Limitations:</b></p> <ul style="list-style-type: none"> <li>- Convenience sampling</li> <li>- No control group.</li> <li>- Limited generalizability as only English speaking participants in 1 setting.</li> </ul>	
<p>One Size Does Not Fit All: Parents' Evaluations of a Support Program in a Newborn Intensive Care Nursery, Hurst, I. (2006). Describe parents' use and assessment of a multi-format NICU parent support program.</p>	<ul style="list-style-type: none"> <li>- Mixed methods: descriptive statistics analysis and qualitative content analysis.</li> <li>- 303 families representing 477 individuals provided data regarding overall use of the parent support program.</li> <li>- 44 families representing 48 individuals</li> </ul>	<ul style="list-style-type: none"> <li>- Parent support program principles are described and association to family centered care approach is apparent.</li> </ul>	<ul style="list-style-type: none"> <li>- Participation results indicate that 78% of participants used 1 format of the support program whereas 18% used 2 formats, and 4% used all 3 formats.</li> <li>- Participation in the hospital visitation format is 89%, 30% utilized the group format, 3% utilized the telephone format.</li> <li>- Survey responses resulted in 6 themes: valuable support,</li> </ul>	<p><b>Strengths:</b></p> <ul style="list-style-type: none"> <li>- Well defined research question.</li> <li>- Ethics review and consent obtained.</li> <li>- Data collection and analysis described.</li> </ul> <p><b>Limitations:</b></p> <ul style="list-style-type: none"> <li>- Convenience sampling used.</li> <li>- Data only collected from English speaking</li> </ul>	<p><b>Weak study:</b> medium to low quality that utilizes direct evidence.</p>

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	<p>completed a survey.</p> <ul style="list-style-type: none"> <li>- Survey consisted of 13, 5 point Likert-type scale questions, demographic questions, and 1 open-ended question.</li> </ul>		<p>emotional support, group support, involvement with baby's care, information support, recommendations for improvement.</p> <ul style="list-style-type: none"> <li>- 92% of survey participants would recommend the parent support program to other NICU families.</li> </ul>	<p>families.</p> <ul style="list-style-type: none"> <li>- Reliability and validity of survey is not described but researchers did pilot the survey and made adjustments based on feedback.</li> <li>- Survey response rate of 23%.</li> </ul>	
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**Table A4**

### Qualitative Research of NICU Parent Education Programs

<p>Implementing Family-Integrated Care in the NICU, Bracht, M., O'Leary, L., Lee, S.K., O'Brien, K. (2013). Describes the development, implementation, and evaluation of the NICU family integrated care</p>	<p>- Narrative review and Case Report</p>	<p>- Philosophy developed that relates to family centered care. - Developed principles of adult learning.</p>	<p>- Provides details on literature review. - Summarizes results of lit. review. - Outlines program's philosophy and teaching strategies. - Describes details of the program's development, implementation, and evaluation. - Promotes individualized learning.</p>	<p><b>Strengths:</b></p> <ul style="list-style-type: none"> <li>- Well defined purpose.</li> <li>- Appropriate methodology with justification.</li> <li>- NICU focused.</li> <li>- Description of setting.</li> <li>- Applied results of a literature review.</li> <li>- Demonstrates</li> </ul>	<p><b>Strong</b> study design with <b>high</b> relevancy due to:</p> <ul style="list-style-type: none"> <li>- Comparable goals, focus, and values.</li> <li>- Evidence is credible as a detailed description of the literature reviewed is supplied.</li> </ul>
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(FIC) parent education and support program.			<ul style="list-style-type: none"> <li>- Provides examples of program content.</li> <li>- Utilizes multiple formats.</li> </ul>	application of family-centered care in the NICU. <ul style="list-style-type: none"> <li>- Applies principles of adult learning.</li> <li>- Collaborates with NICU families and HCPs.</li> </ul> <b>Limitations:</b> <ul style="list-style-type: none"> <li>- Pilot program.</li> <li>- Program requires multiple support personnel.</li> </ul>	<ul style="list-style-type: none"> <li>- Further formalized research needs to be conducted in order to understand the program's ability to be implemented in other units.</li> </ul>
A Systematic Mapping Review of Effective Interventions for Communicating with, Supporting and Providing Information to Parents of Preterm Infants, Brett, J., Staniszewska, S., Newburn, M., Jones, N., Taylor, L. (2011). Describes results	<ul style="list-style-type: none"> <li>- Literature Review: metasynthesis.</li> <li>- 72 articles with details of inclusion criteria outlined.</li> </ul>	<ul style="list-style-type: none"> <li>- Discusses relevance to family centered care.</li> </ul>	<ul style="list-style-type: none"> <li>- Reviews interventions to support parents with preterm infants.</li> <li>- Discusses key communication strategies.</li> <li>- Identified the importance of promoting parent involvement in the NICU in order to facilitate parent coping, improve infant outcomes, and reduce length of hospital stay.</li> <li>- Outlines interventions/content at various stages along the</li> </ul>	<b>Strengths:</b> <ul style="list-style-type: none"> <li>- Well defined research question.</li> <li>- Inclusion criteria provided and appropriate with justification.</li> <li>- Comprehensive search on multiple databases and grey literatures.</li> <li>- Articles screened by two reviewers.</li> </ul>	<b>Strong</b> study design with <b>high</b> quality literature review that applies methodology appropriately and includes implications to nursing practice and critical appraisal of articles <ul style="list-style-type: none"> <li>- Consistent results.</li> </ul>



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from the first phase of the POPPY project that investigates the literature associated with effective interventions for communicating, supporting, and providing information to parents of preterm infants.			NICU journey. - Describes various formats that can be used.	- Appropriate analysis and discussion of results. <b>Limitations:</b> - Literature of varying quality reviewed. - Literature from more than one country included.	- Use of direct evidence and implications to nursing practice.
Family Support and Education, Goldstein, L.A. (2013). Describes a NICU discharge path using evidence to support this program's development and implementation.	- Narrative Review and Case Report - Designed for use in the NICU	- Discusses features of family centered care and adult learning.	- Identifies NICU families' needs. - Promotes individualized learning plans. - Promotes repeating and reinforcing education. - Parent-directed program. - Provides examples of formats and content.	<b>Strengths:</b> - Well defined purpose. - NICU focused. - Applied results of a literature review. - Demonstrates application of family-centered care in the NICU. <b>Limitations:</b> - No description of sample or setting. - Poor description of literature review.	<b>Strong</b> study design with <b>high</b> relevancy due to: - Comparable goals, focus, and values. - Detailed description and rationale for program's content and formats. - Poor description of the literature used for the development of the program.

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<p>The POPPY Study: Developing a Model of Family-Centered Care for Neonatal Units, Staniszewska et al. (2012). Develop, with NICU families, the POPPY model of family-centered care by integrating the results from high quality research studies that focused on parent experiences and effective interventions.</p>	<ul style="list-style-type: none"> <li>- Mixed methods, descriptive, cross-sectional design and systematic literature review.</li> <li>- 2 Qualitative studies were based in the UK.</li> <li>- 1 Systematic review included international studies.</li> </ul>	<ul style="list-style-type: none"> <li>- Family Centered Care focusing on communication, information, and support.</li> <li>- Based on evidence, the POPPY philosophy and principles were identified and defined.</li> </ul>	<ul style="list-style-type: none"> <li>- Family Centered Care is highly valued but it's difficult to apply to practice.</li> <li>- Defined each stage within the model developed and provided suggestions on parent needs in each stage.</li> </ul>	<p><b>Strengths:</b></p> <ul style="list-style-type: none"> <li>- Strong evidence base and parent involvement.</li> <li>- Well defined philosophy and principles.</li> <li>- Well defined and relevant research question.</li> <li>- Methodology appropriate and justified.</li> <li>- Sampling criteria described.</li> <li>- Ethics approval and consent obtained.</li> <li>- Collaborated with NICU families during entire process.</li> </ul> <p><b>Limitations:</b></p> <ul style="list-style-type: none"> <li>- UK based study that only explores experiences within the UK.</li> <li>- Sampling strategy not described.</li> </ul>	<p><b>Strong</b> study design with <b>high</b> quality synthesis of research studies that utilize direct evidence.</p>
Development and	- Case report.	- Family-centered	- Outlines key stages	<b>Strengths:</b>	<b>Moderate</b> study

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<p>Dissemination of Potentially Better Practices for the Provision of Family-Centered Care in Neonatology: The Family-Centered Care Map, Dunn, M.S., Reilly, M.C., Johnston, A.M., Hoopes, R.D., Abraham, M.R. (2006). Demonstration of how to apply family-centered approach within the NICU that meet the needs of NICU families throughout their NICU journey.</p>	<p>- 3 NICUs within the Vermont Oxford Network.</p>	<p>care.</p>	<p>within an infant's NICU journey. - Outlines key interventions by health care professionals that ensure a family-centered approach. - Organizes the interventions that can be employed during the key stages of a family's journey in the NICU to ensure application of family-centered care.</p>	<p>- Similar setting. - Collaboration between 3 NICUs and a NICU parent. - Interventions were developed by applying results of a literature review of NICU parent experiences. - Demonstrates application of family-centered care in the NICU. <b>Limitations:</b> - No follow-up data. - Need further input from family advisor committees.</p>	<p>design with <b>medium</b> relevancy due to: - Comparable goals, processes, and values. - Family-centered care map concentrates more on guiding health care professionals but remains applicable to the development of a guide that targets families but limited description the evidence used to develop this guide would improve its credibility.</p>
<p>Instituting Parent Education Practices in the Neonatal Intensive Care Unit: An Administrative Case Report of Practice Evaluation and Statewide</p>	<p>-Case Report (evaluative) - Tertiary care, 36-bed NICU in Virginia.</p>	<p>- Developmentally supportive care.</p>	<p>- Description of the evaluation, development, and implementation of a NICU parent education program. - Demonstrates the importance of collaboration, early</p>	<p><b>Strengths:</b> - Similar setting. - Detailed description of education program. <b>Limitations:</b> - Poor description</p>	<p><b>Moderate</b> study design with <b>medium</b> relevancy due to: - Comparable goals, focus, and values. - Implications to</p>

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Action, Dusing, S.C., Van Drew, C.M., & Brown, S.E. (2012). A case report that describes the development, implementation, and evaluation of a NICU parent education program that included interdisciplinary collaboration.			introduction to education, and use of multiple formats.	of data collection methods. - Focus is on allied health contributions with minimal involvement of the entire health care team.	practice included.
Preparing Parents for NICU Discharge: An Evidence-Based Teaching Tool, Schlittenhart, J.M., Smart, D., Miller, K., Severtson, B. (2011). Description of the development of a NICU discharge DVD/video.	- Narrative Review and Case Report - Designed for use in the NICU	- Discusses features of adult learning.	- Identifies NICU families' informational needs. - Promotes individualized learning. - Promotes repeating and reinforcing education. - Parent-directed program. - Provides examples of content. - Describes benefits to using DVD/video. - Summarized the development plan and who was involved contributed.	<b>Strengths:</b> - Well defined purpose. - NICU focused. - Applied results of a literature review. - Demonstrates application of adult learning theory. <b>Limitations:</b> - Poor description of setting. - Poor description of literature review.	<b>Moderate</b> study design with <b>medium</b> relevancy due to: - This report describes the application of evidence and collaboration with NICU health care team members to develop a discharge teaching DVD/video but more detailed description of the literature review and setting would

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					improve the credibility of the content.
Parenting Preemies: A Unique Program for Family Support and Education after NICU Discharge, Willis, V.(2008). Description of the hospital based, multi-format, parenting preemies program.	-Case Report	- Discusses features of family centered care.	- Promotes individualized learning. - Content is evidenced based. - Utilizes multiple formats. - Content is described. - Multidisciplinary approach.	<b>Strengths:</b> - Well defined purpose. - NICU focused. - Description of setting. - Demonstrates application of family-centered care in the NICU. - Collaborates with NICU HCPs. <b>Limitations:</b> - Limited description of evidence used to develop program. - Limited description on who was involved in developing program.	<b>Moderate</b> study design with <b>medium</b> relevancy due to: - Comparable goals, focus, and values. - Detailed description of program. - Potential need for input from NICU families. - Unable to easily determine credibility of evidence used to develop program. - Further formalized research needs to be conducted in order to understand the program's ability to be implementation in other units.

## Appendix B

### Health Research Ethics Authority Screening Tool for Needs Assessment

	Question	Yes	No
1.	Is the project funded by, or being submitted to, a research funding agency for a research grant or award that requires research ethics review	<input type="checkbox"/>	<input checked="" type="checkbox"/>
2.	Are there any local policies which require this project to undergo review by a Research Ethics Board?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
	<b>IF YES</b> to either of the above, the project should be submitted to a Research Ethics Board. <b>IF NO</b> to both questions, continue to complete the checklist.	<input type="checkbox"/>	<input checked="" type="checkbox"/>
3.	Is the primary purpose of the project to contribute to the growing body of knowledge regarding health and/or health systems that are generally accessible through academic literature?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
4.	Is the project designed to answer a specific research question or to test an explicit hypothesis?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
5.	Does the project involve a comparison of multiple sites, control sites, and/or control groups?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
6.	Is the project design and methodology adequate to support generalizations that go beyond the particular population the sample is being drawn from?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
7.	Does the project impose any additional burdens on participants beyond what would be expected through a typically expected course of care or role expectations?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
<b>LINE A: SUBTOTAL Questions 3 through 7 = (Count the # of Yes responses)</b>		<b>0</b>	
8.	Are many of the participants in the project also likely to be among those who might potentially benefit from the result of the project as it proceeds?	<input checked="" type="checkbox"/>	<input type="checkbox"/>
9.	Is the project intended to define a best practice within your organization or practice?	<input checked="" type="checkbox"/>	<input type="checkbox"/>
10.	Would the project still be done at your site, even if there were no opportunity to publish the results or if the results might not be applicable anywhere else?	<input checked="" type="checkbox"/>	<input type="checkbox"/>
11.	Does the statement of purpose of the project refer explicitly to the features of a particular program, Organization, or region, rather than using more general terminology such as rural vs. urban populations?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
12.	Is the current project part of a continuous process of gathering or monitoring data within an organization?		<input checked="" type="checkbox"/>
<b>LINE B: SUBTOTAL Questions 8 through 12 = (Count the # of Yes responses)</b>		<b>3</b>	
<b>SUMMARY: Line A = 0; Line B = 3</b>			

#### Interpretation

The sum of Line B is greater than Line A and so the most probable purpose of this needs assessment is quality/evaluation and does not require review by an ethics board.

## Appendix C

### Discussion Guide for FHA NICU Shared Work Team

#### Question 1

In your experience, what have parents told you about their informational needs?

#### Question 2

What questions do parents consistently ask you?

#### Table C1

#### Responses from FHA NICU Shared Work Team Consultation

Informational Gathering Questions	Responses
Where	- Parents like to receive information at their baby's bedside
Who	- From neonatologists - Parents look for support from a variety of people, including health care professionals
When	- Parents like to have regular updates about their baby from the neonatologists - Parents ask the same questions more than once - Parents informational needs change as their baby normalizes/matures - Parents often ask more questions once they are able to participate more in their baby's care - Initially, parents ask questions about the technology being used such as the monitor, leads, incubator, ventilator - When parents become more involved in their baby's care they ask more questions about their baby's cues and various behaviours - Parents want to know when significant changes to their baby occur
Why	- Parents want to know why decisions about their baby's medical care are made
How	- Parents do well when health care professionals provide them with confidence - Parents require updates using lay terms versus medical terminology - Parents want assistance communicating with the healthcare team - Parents like to be reassured - Some parents like written material, others prefer classes, one to one education, and/or hands on experience with guidance - Parents want to know how to advocate for their baby - Parents want to know how they can assume their parental role

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What	<ul style="list-style-type: none"><li>- Parents like to know what to expect</li><li>- Mother's needs often differ from father's needs</li><li>- Parents are eager to learn but are not sure what they need to know</li><li>- Parents want to know if they are doing the best for their baby and/or what is the best for their baby</li></ul> <p>Parents often ask about the following:</p> <ul style="list-style-type: none"><li>• NICU 'routines' and 'rules'</li><li>• when their baby can go home</li><li>• specific health challenges (such as jaundice, respiratory distress, patent ductus arteriosus)</li><li>• infant feeding</li><li>• their baby's sleep/wake cycles</li><li>• weight gain</li><li>• changes in their baby's clinical status</li></ul>
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**Appendix D**

**Discussion Guide for NICU Family Consultations**

- 1) What education have you received in the NICU?
  - a. When did you receive this information?
  - b. How helpful was this information, was it easy to understand?
  - c. Was there any specific education that helped you become more comfortable with becoming more involved in your baby's care?
  - d. Was there any information that was unnecessary?
  - e. What education would you recommend to other NICU families?
- 2) What education would you like to have received?
  - a. When would you have liked to receive this education?
- 3) Do you think having a list of the official information/education available in the NICU would be helpful?
- 4) How do you like education to be delivered?  
Written/Classes/Videos/Photos/Online/ Other
- 5) Do you have any other comments or suggestions about NICU family education?

## Appendix E

## Summary of FHA NICU Family Consultation

Table E1

## Feedback for Current FHA Family Education

What education have you received in the NICU?	When did you receive this information?	How helpful was this information?	Was this information easy to understand?	Did this information help you become more comfortable with becoming more involved in your baby's care?	Was this information unnecessary?	Would you recommend this education to other NICU families?
- One on one with Neonatologist and Nurse	- Prenatally	- Helpful	- Yes			- Yes
- Breastfeeding and information on PROM	- Prenatally	- Helpful				
- Neo consult	- Prenatally	- Very Helpful				
- What to expect	- Prenatally	- Very helpful				
- What to expect with a photobook	Prenatally	- Very Helpful				
- NICU tour	- Admission	- Very Helpful				
- Rounds, description	- Admission	- Helpful				

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of clinical interventions						
NICU team members, breastfeeding, parents role	- Admission	- Very helpful				
NICU classes schedule	- Admission	- Helpful				
- Welcome pamphlet	- Admission	- Somewhat	- Yes	- No	- Somewhat	- Yes
- Welcome brochure, classes		- Helpful				
- Welcome to the NICU class		- Helpful	- Yes	- Neutral	- Yes	- Yes
- Welcome pamphlet	- Admission	- Very Helpful	- Yes			
- Information about the role of the NICU, lactation, pumping	During the 1 <sup>st</sup> week	- Helpful				
- Definitions of common medical terms, family room, resources, how parents can support their baby	- 1 <sup>st</sup> week	- Very helpful				
- Orientation to the NICU	- 1 <sup>st</sup> week	- Helpful				
- Explanation of best way to handle my baby, description of NICU technology, What to expect	After the 1 <sup>st</sup> week	- Very Helpful				
- Feeding class		- Helpful	- Yes	- Neutral	- Yes	- Yes
- Development		- Helpful	- Yes	- No		- Maybe

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- Hearing, parent tea		- Not helpful				
- Caring for my baby class and airway management		- Very helpful	- Strongly Agree	- Strongly Agree	- No	- Yes
- Airway Management		- Very Helpful	Strongly Agree	- No	- Yes	- Yes
- Airway Management		- Helpful	- Yes	- Neutral	- Yes	- Yes
- Airway management and car seat		- Agree	- Agree	- Agree	- no	- Yes
- Car seat, getting to know my baby, airway management, feeding at home, breastfeeding, going home development		- Helpful	- Agree	- Strongly Agree	- No	- Yes
- Car Seat class		- Helpful	- Yes	- Neutral	- Yes	- Yes
- Car seat	After the first week	-Neutral	- Yes	- Agree		- Yes
- Car seat		- Helpful	- Strongly Agree	- Strongly Agree	- No	- Yes
- Car seat		- Very Helpful	Strongly Agree	- No	- Yes	- Yes
- Car Seat		- Helpful	- Yes	- No		- Maybe
- Car seat		- Very Helpful	- Strongly Agree	- Strongly Agree	- No	- Yes
- Going Home class		- Helpful	- Yes	- Neutral	- Yes	- Yes

## **NICU Family Education Recommendations**

### **Prenatal education recommendations.**

- |  |  |  |
|--|--|--|
| - Baby's best chance   | - Expected milestones for premature babies             | - What to expect, the NICU journey, the NICU environment, Health care team members           |
| - Developmental facts, types of procedures, and description of equipment | - Differences between premature babies and term babies | - Description of the NICU, success stories, outcomes of prematurity, primary nursing, rounds |
| - What to expect   | - Description of the FHA NICUs and their capabilities  | - What to expect, how to parent in the NICU, balancing NICU and home life                    |

### **Admission education recommendations.**

- Potential health challenges
- What to expect, how to help my baby grow and develop
- Orientation to the NICU: contact information, how to be involved in baby's care, classes, benefits of skin to skin, ways to connect with other families, NICU policies (HH, visitors, health screening), members of the health care team, parking

### **During the first week education recommendations.**

- Check in by staff members
- How to support my baby

### **After the first week education recommendations.**

- Opportunities available such as pamphlets, participation in baby's care, classes
- Help with the paperwork for financial support and claims
- Contact information

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- Follow-up check in by staff members

### **Other education recommendations.**

- More help when being transferred to a new unit
- Information about NICU routines
- Regular Clinical Updates
- Changes to my baby's care plan
- Councillors
- Family Education Resource Room
- List of available education
- More consistent education within FHA NICUs
- Education at infant's bedside
- Reinforced and repeated education
- Varying class times
- Consistent updates from the Neonatologists
- More emotional support from the staff
- Opportunities to connect with other NICU families
- Make sure the staff allow parents to be involved in my baby's care
- I was overwhelmed by the amount of information provided to me

**Table E2**

### **Education Delivery Preferences**

<b>Format</b>	<b>Number of families who stated this as their preference</b>
Written	7
Classes	7
Videos	7
Photos	5

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Online	6
Other	<ul style="list-style-type: none"><li>- Face to face</li><li>- Hands on</li><li>- NICU graduate family support</li><li>- Conversations</li></ul>

## **Appendix F**

### **Discussion Guide for the Meeting with Patient Education Consultant**

- 1) Can you provide the team with an overview of how the patient education department can assist with this project?
- 2) You have had the opportunity to review our mission, goals, and objectives. Do you have any feedback for the team with regards to our project plan?
- 3) We are conducting an environmental scan of available resources that relate to this project. At this time we are aware of the FHA patient education catalogue but, in your opinion, what are there any other resources we should explore?
- 4) What formats does your department specialize in?
- 5) Ask if team members have any other questions for the patient education consultant.



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**Table F1**

### **Minutes for the Patient Education Consultant Meeting**

<b>Discussion Topic</b>	<b>Summary of Discussion</b>	<b>Action Items</b>
Overview of the patient education department	<p>The patient education department provides support and expertise to FHA initiatives that involve the production of patient education material. Specific areas that they provide assistance with is in print based material, copyright permission, and an image catalogue.</p> <p>The department also provides workshops to help FHA employees develop patient education material. Customized workshops for specific needs can also be provided.</p> <p>The patient education department also gathers statistics such as how many times a resource is downloaded.</p> <p>The patient education has also developed numerous relationships with patient education resources outside of FHA. If there is a noted gap in FHA patient education the department will help employees or groups connect with organizations that may have a resource that would benefit FHA patients and families.</p>	
Feedback for our project plan	The plan the team has developed is comprehensive and suitable. It is recommended to keep the patient education department remain involved in all aspects of the project.	Plan to forward all meeting minutes to the patient education consultant.
Resources for FHA patient education for environmental scan	<p>Current FHA resources include the patient education catalogue, Health Link BC, and Best Beginnings website.</p> <p>Other potential sources that would require further assessment and approval include The Hospital for Sick Children, BC Women's Hospital and Health Centre, Capital Health Nova Scotia, Alberta Health Services, Vancouver Coastal Health, Hamilton Health Services, and Cincinnati Children's Hospital Medical Center.</p>	Recommend to develop a list of current available resources in FHA first.
Available formats and	FHA patient education department focuses on print based material (which	Plan to contact

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languages	includes appropriate language, layout, and images). FHA employees contact information that can assist with the development of video's and website associated content provided. There are also translation services available within FHA's cultural department. The usual process for translation is to develop the material in English first and then consult translation services. Translation service can recommend what languages would best meet the population of your area.	employees that will assist with videos and website content when at the development of new patient education stage is reached.
Ask if team members have any other questions for the patient education consultant	Discussed how to obtain a catalogue number for the patient education catalogue.	

**Appendix G****Environmental Scan****Table G1****FHA Patient Education Catalogue**

<b>Topic</b>	<b>Source/Format</b>	<b>Languages (other than English)</b>
Baby's Immune system and vaccines	pamphlet	
Best Beginnings	pamphlet	
Breastfeeding	Health link file	Chinese, French, Punjabi, Spanish, Vietnamese
Breast Pump	pamphlet	
Beyond the Baby Blues	pamphlet	Punjabi
Car Seat Safety	pamphlet	
Car Seat Safety for Tiny Babies Safe Ride News	pamphlet	
Car Seat: pamphlet (Rear facing car seats from Transport Canada)	pamphlet	
Breast Pump: Pamphlet	pamphlet	
Caring for substance exposed babies	pamphlet	
Chickenpox (Varicella) Vaccine	Healthlink file	Chinese, French, Punjabi, Spanish, Vietnamese
Caring for substance exposed babies	pamphlet	
Clean Hands Protect Your Baby	pamphlet	Korean, Punjabi, Chinese, Simplified Chinese
Communicating with your baby	pamphlet	
Diphtheria, Tetanus, Pertussis, Hep B, Polio & DTaP-HB-IPV-Hib Vaccine	Healthlink file	Chinese, French, Punjabi, Spanish, Vietnamese
Donor human milk (about donating your milk)	pamphlet	
Donor human milk (for potential milk donors)	pamphlet	
Every Sleep Counts!	pamphlet	Spanish, Vietnamese, Punjabi, Korean, Simplified Chinese, Chinese

# NEEDS ASSESSMENT FOR A NICU FAMILY EDUCATION GUIDE

Expressing Your Breastmilk	pamphlet	
Feeding your baby in the NICU: Information to help with decisions	pamphlet	
Feeding your Baby safely	pamphlet	
Formula Feeding your baby: birth to 6 months	pamphlet	
Gastroesophageal Reflux Disease	about kids health link	
Feeding your baby in the NICU: Information to help with decisions	pamphlet	
Feeding your Baby safely	pamphlet	
Formula Feeding your baby: birth to 6 months	pamphlet	
Gastroesophageal Reflux Disease	about kids health link	
Help your baby practice sucking	pamphlet	
Hernia	about kids health link	Chinese
Hepatitis B Infant Vaccine	Healthlink file	Chinese, French, Punjabi, Spanish, Vietnamese
Help your baby practice sucking	pamphlet	
Hypoxic-Ischemic Encephalopathy (HIE) and Normothermia Treatment	pamphlet	
Hypoxic-Ischemic Encephalopathy (HIE) and Hypothermia Treatment	pamphlet	
Inactivated Influenza (Flu) Vaccine	HealthLink file	Chinese, French, Punjabi, Spanish, Vietnamese
Jaundice	pamphlet	
Jaundice	about kids health link	Chinese, Punjabi
Measles, Mumps, Rubella (MMR) Vaccine	Healthlink file	Chinese, French, Punjabi, Spanish, Vietnamese
Meningococcal C Conjugate (Men-C) Vaccine	Healthlink file	Chinese, French, Punjabi, Spanish, Vietnamese
Meningococcal Quadrivalent Vaccines	Healthlink file	Chinese, French, Punjabi, Spanish, Vietnamese
Nipple shield	pamphlet	
Perinatal Loss:	pamphlet	

## NEEDS ASSESSMENT FOR A NICU FAMILY EDUCATION GUIDE

Pneumococcal Conjugate (PCV 13) Vaccine	Healthlink BC	Chinese, French, Punjabi, Spanish, Vietnamese
Baby Flat-Head (Plagiocephally): Treatment with a Corrective Helmet	about kids health link	
Rotavirus Vaccine	Healthlink BC	
Respiratory Syncytial Virus (RSV)	Healthlink BC	Chinese, French, Punjabi, Spanish, Vietnamese
Safe Sleeping for Babies	Healthlink file	Chinese, French, Punjabi, Spanish, Vietnamese
Skin to Skin cuddling	pamphlet	
Starting Solid Foods for Premature Babies	pamphlet	
Vitamin D for babies & toddlers	pamphlet	Punjabi, Chinese, Chinese simplified, Korean, Arabic
Welcome to the NICU, Abbotsford Hospital	pamphlet	
Welcome to the NICU , Burnaby Hospital	pamphlet	
Welcome to the NICU, Royal Columbian Hospital	pamphlet	
Welcome to the NICU, Surrey Memorial Hospital	pamphlet	
Your Late Preterm Baby	pamphlet	

**Table G2**

### **Patient Education not on Patient Education Catalogue (not available throughout FHA)**

<b>Topic</b>	<b>Location (if known)</b>	<b>Department</b>	<b>Format</b>
Airway Management	Abbotsford Hospital, Royal Columbian Hospital, and Surrey Memorial Hospital	Respiratory Therapy	class
Brachial plexus	Royal Columbian Hospital and Surrey Memorial Hospital	Physiotherapy	pamphlet
Car Seat	Abbotsford Hospital, Royal Columbian Hospital, and Surrey Memorial Hospital	Physiotherapy	class
Care by Parent Room	Abbotsford Hospital		

# NEEDS ASSESSMENT FOR A NICU FAMILY EDUCATION GUIDE

Caring for Your Baby Pamphlet	Royal Columbian Hospital	Registered Nurse	class
Clubfoot	Royal Columbian Hospital and Surrey Memorial Hospital	Physiotherapy	pamphlet
Coping while your baby is in the NICU	Royal Columbian Hospital	Social Work	class
Developmental activities	Surrey Memorial Hospital	Physiotherapy	pamphlet
Family Care Plan	Surrey Memorial Hospital	Discharge Planning Nurse	care plan
Feeding your baby at home	Royal Columbian Hospital	Registered Dietician	class
Getting to Know Your Baby	Royal Columbian Hospital and Surrey Memorial Hospital	Occupational Therapy	class
Going Home from the NICU & Developmental Play	Royal Columbian Hospital and Surrey Memorial Hospital	Occupational Therapy	class
Hand Expression	Royal Columbian Hospital	Lactation Consultant and Occupational Therapy	Video
Helping you baby learn to feed	Surrey Memorial Hospital	Occupational Therapy and Speech Language Pathology	
Increasing milk supply		Lactation Consultant	
Kudos for Cuddling	Royal Columbian Hospital	Occupational Therapy	pamphlet
Laminated Developmental Care and how to interact with your baby	Surrey Memorial Hospital		
Late Preterm Infant Developmental Activities	Surrey Memorial Hospital	Physiotherapy	pamphlet
Milk Expression Record		Lactation Consultant	pamphlet
NICU info package	Royal Columbian Hospital	Occupational Therapy	
Parent Tea (monthly)	Royal Columbian Hospital and Surrey Memorial Hospital	Social Work	support group
Plagiocephaly	Royal Columbian Hospital and Surrey Memorial Hospital	Physiotherapy	
Photobooks for Prenatal Consults	Royal Columbian Hospital	Registered Nurse	photobook

# NEEDS ASSESSMENT FOR A NICU FAMILY EDUCATION GUIDE

Synagis	All	Pharmacy	pamphlet
Torticollis	Royal Columbian Hospital and Surrey Memorial Hospital	Physiotherapy	pamphlet

**Table G3**

## Topics Available on Health Link BC

Topic	Format/Language
<b>Breastfeeding:</b>	
Breastfeeding	<b>Healthlink File</b> / English, Chinese, French, Punjabi, Spanish, Vietnamese
Breast Engorgement	<b>Link</b>
Breastfeeding Positions	<b>Link</b>
Choosing a Breast Pump	<b>Link</b>
Feeding Schedule for Babies	<b>Link</b>
How to Use a Breast Pump	<b>Link</b>
Mastitis	<b>Link</b>
Medicine Use While Breastfeeding	<b>Link</b>
Nutrition While Breastfeeding	<b>Link</b>
Sore Nipples	<b>Link</b>
Storing Breast Milk	<b>Link</b>
<b>Formula Feeding:</b>	
Feeding Schedule for Babies	<b>Link</b>
Getting Started	<b>Healthlink File</b> / English, Chinese, French, Punjabi, Spanish, Vietnamese
Preparing and Storing	<b>Healthlink File</b> / English, Chinese, French, Punjabi, Spanish, Vietnamese
Choosing Baby Bottles and Nipples	<b>Link</b>
<b>Immunizations:</b>	
Your baby's immune system and vaccines	<b>Healthlink File</b> / English, Chinese, French, Punjabi, Spanish, Vietnamese
Immunization schedule	<b>Healthlink File</b> / English, Chinese, French, Punjabi, Spanish, Vietnamese
Childhood Vaccines are Safe	<b>Healthlink File</b> / English, Chinese, French, Punjabi, Spanish, Vietnamese

# NEEDS ASSESSMENT FOR A NICU FAMILY EDUCATION GUIDE

Better Immunization Experience for Your Child	<b>Healthlink File</b> / English, Chinese, French, Punjabi, Spanish, Vietnamese
The Benefits of Immunizing Your Child	<b>Healthlink File</b> / English, Chinese, French, Punjabi, Spanish, Vietnamese
<p>Types of vaccines:</p> <p>Chickenpox (Varicella) Vaccine</p> <p>Diphtheria, Tetanus, Pertussis, Hepatitis B, Polio, and Haemophilus influenzae type b (DTaP-HB-IPV-Hib) Vaccine</p> <p>Diphtheria, Tetanus, Pertussis, Polio (DTaP-IPV) Vaccine</p> <p>Diphtheria, Tetanus, Pertussis, Polio, Haemophilus influenzae Type b (DTaP-IPV-Hib) Vaccine</p> <p>Hepatitis A Vaccine</p> <p>Hepatitis B Vaccine</p> <p>Human Papillomavirus (HPV) Vaccine</p> <p>Inactivated Influenza (Flu) Vaccine Live</p> <p>Attenuated Influenza (Flu) Vaccine</p> <p>Measles, Mumps, Rubella (MMR) Vaccine</p> <p>Measles, Mumps, Rubella and Varicella (MMRV) Vaccine</p> <p>Meningococcal C Conjugate (Men-C) Vaccine</p> <p>Pneumococcal Conjugate (PCV 13) Vaccine</p> <p>Pneumococcal Polysaccharide Vaccine</p> <p>Rotavirus Vaccine Tetanus and Diphtheria (Td) Vaccine</p> <p>Tetanus, Diphtheria, Pertussis (Tdap) Vaccine</p>	<b>Healthlink File</b> / English, Chinese, French, Punjabi, Spanish, Vietnamese
<b>Newborn Screening:</b>	
Newborn Screening Test	<b>Healthlink File</b> / English, Chinese, French, Punjabi, Spanish, Vietnamese
Phenylketonuria (PKU)	<b>Link</b>
<b>Premature Infant</b>	
<i>Development:</i>	
Cognitive Development	<b>Link</b>
Growth and Development	<b>Link</b>
Stimulate Your Baby's Learning	<b>Link</b>
<i>Respiratory:</i>	
Caring for Your Baby's Nasal Cannula	<b>Link</b>
Chronic Lung Disease in Infants	<b>Link</b>
Delivery of a Premature Infant	<b>Link</b>



# NEEDS ASSESSMENT FOR A NICU FAMILY EDUCATION GUIDE

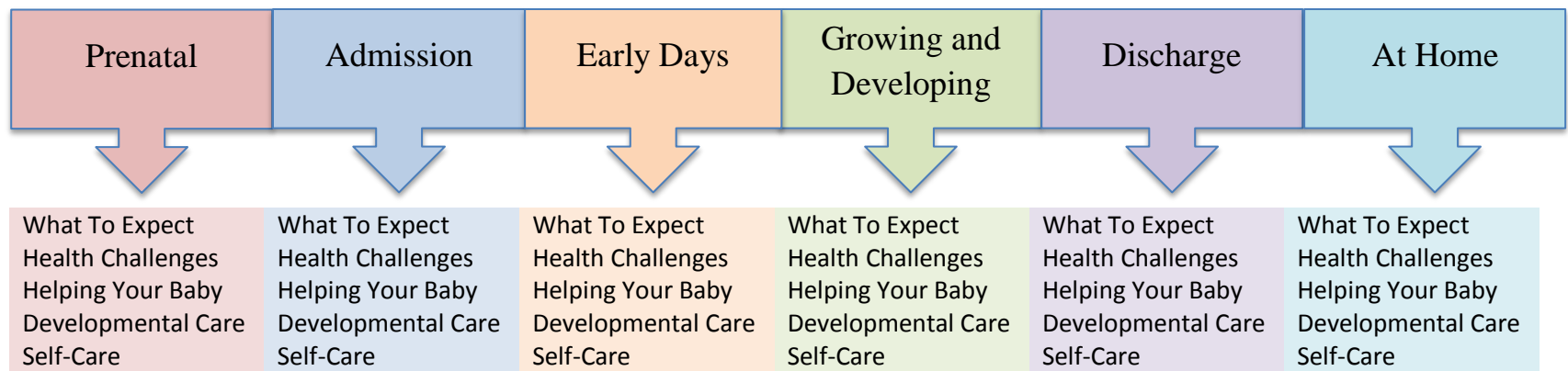
FAQ	<b>Link</b>
Feeding your Premature Infant	<b>Link</b>
Getting to Know the NICU	<b>Link</b>
Immunizations for Premature Infants	<b>Link</b>
Jaundice in Newborns	<b>Link</b>
Making Decisions About Very Premature Infants	<b>Link</b>
NEC	<b>Link</b>
NICU Communicating with the Staff	<b>Link</b>
Premature Infant Topic Overview	<b>Link</b>
Signs of Overstimulation	<b>Link</b>
Taking Care of Yourself	<b>Link</b>
Taking Your Baby Home	<b>Link</b>
The First Week at Home	<b>Link</b>
The Premature Newborn	<b>Link</b>
The Sick Premature Newborn	<b>Link</b>
Treating Underdeveloped Lungs	<b>Link</b>
What to Expect When you Have an Extremely Premature Infant	<b>Link</b>
Baby Blues	<b>Link</b>
Care Seats	<b>Link</b>
Caring for More than One Baby	<b>Link</b>
Congenital Torticollis	<b>Link</b>
Development	<b>Healthlink File</b> / English, Chinese, French, Punjabi, Spanish, Vietnamese
Feeding Your Infant	<b>Link</b>
Fontanelles and Sutures of the Infant Skull	<b>Link</b>
Gastroesophageal Reflux in Babies and Children	<b>Link</b>
Handwashing	<b>Healthlink File</b> / English, Chinese, French, Punjabi, Spanish, Vietnamese
Phototherapy for Jaundice in Newborns	<b>Link</b>
Positional Plagiocephaly	<b>Link</b>
Routine Checkups	<b>Link</b>
RSV	<b>Link</b>
Safe Sleeping for Babies	<b>Healthlink File</b> / English, Chinese, French, Punjabi, Spanish, Vietnamese
Shaken Baby Syndrome	<b>Healthlink File</b> / English, Chinese, French, Punjabi, Spanish, Vietnamese
SIDS	<b>Healthlink File</b> / English, Chinese,

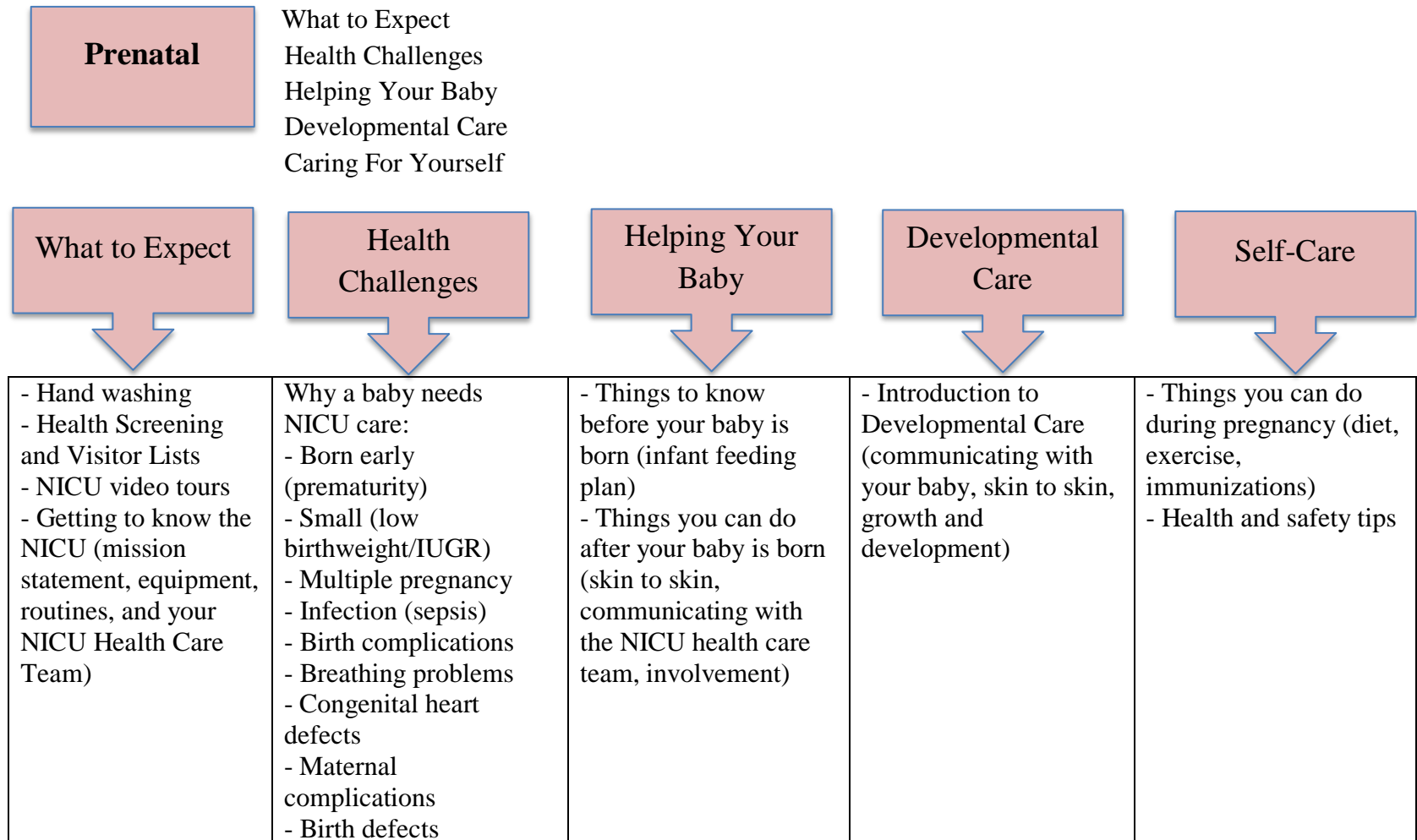
## NEEDS ASSESSMENT FOR A NICU FAMILY EDUCATION GUIDE

	French, Punjabi, Spanish, Vietnamese
Sudden Infant Death Syndrome	<b>Link</b>
Your Child and Play (birth to 3 years)	<b>Healthlink File</b> / English, Chinese, French, Punjabi, Spanish, Vietnamese

## Appendix B

### Organization and Content of the NICU Online Guide





## Admission

What to Expect  
Health Challenges  
Helping Your Baby  
Developmental Care  
Caring For Yourself

### What to Expect



### Health Challenges



### Helping Your Baby



### Developmental Care



### Self-Care



<ul style="list-style-type: none"> <li>- Common treatments, tests, and consent</li> <li>- Transfers and NICU level of care</li> <li>- Introduction to the NICU (include coming to (visiting) the NICU, Family areas, Safety, privacy, and security)</li> </ul>	<ul style="list-style-type: none"> <li>- NICU care of the late premature infant, the premature and the extremely premature infant</li> <li>- NICU care of a baby with birth complications</li> <li>- NICU care of a baby with an infection (sepsis)</li> <li>- NICU care of a baby with breathing problems</li> <li>- NICU care of a baby with congenital heart defects</li> <li>- NICU care of a baby with maternal</li> </ul>	<ul style="list-style-type: none"> <li>- Breastfeeding</li> <li>- Expressing breast milk</li> <li>- Storing breast milk</li> </ul>	<ul style="list-style-type: none"> <li>- Hand hugs</li> </ul>	<ul style="list-style-type: none"> <li>- Tips for families</li> <li>- NICU education / Welcome to Holland</li> <li>- Nutrition and medicine use while breastfeeding</li> </ul>
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	complications - NICU care of a baby with birth defects			
Ensure links to: Prenatal - Hand washing - Health Screening and Visitor Lists - NICU video tours - Getting to know the NICU	Ensure links to: - Prenatal Health Challenges - Equipment (prenatal), treatments and tests (admission) - Weight conversion charts and growth and development	Ensure links to: - Infant feeding plan - Skin to skin - Communicating with the healthcare team	Ensure links to: - Prenatal developmental care	Ensure links to: - NICU health care team

## Early Days

What to Expect  
Health Challenges  
Helping Your Baby  
Developmental Care  
Caring For Yourself

### What to Expect

### Health Challenges

### Helping Your Baby

### Developmental Care

### Self-Care

<ul style="list-style-type: none"> <li>- Family Care Plan</li> <li>- Communicating with the NICU team/staying informed</li> </ul>	<ul style="list-style-type: none"> <li>- Complications in the NICU: NEC, Sepsis, Jaundice, PDA</li> </ul>	<ul style="list-style-type: none"> <li>- Primary nurses</li> <li>- Feeding (getting started/formula feeding)</li> <li>- Involvement: Read to your baby, Help your baby practice sucking</li> <li>- Begin to participate in baby care skills</li> </ul>	<ul style="list-style-type: none"> <li>- Signs of Overstimulation</li> <li>- Communicating with your baby</li> <li>- Becoming involved in your baby's care</li> <li>- Waking and Sleeping</li> <li>- Baby Talk</li> </ul>	<ul style="list-style-type: none"> <li>- Family Centered Care</li> <li>- Sore nipples</li> <li>- Breast engorgement</li> <li>- Coping with stress and grief</li> <li>- Reflection through journaling</li> <li>- Sources of support</li> <li>- Bonding</li> </ul>
Ensure links to: <ul style="list-style-type: none"> <li>- NICU routines</li> </ul>	Ensure links to: <ul style="list-style-type: none"> <li>- Prenatal Health Challenges</li> </ul>	Ensure links to: <ul style="list-style-type: none"> <li>- developmental care</li> <li>- Breastfeeding,</li> </ul>		Ensure links to: <ul style="list-style-type: none"> <li>- Primary nursing</li> <li>- Tips for families</li> </ul>

	- Equipment (prenatal), treatments and tests	expressing, and storing milk		
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## Growing and Developing

What to Expect  
Health Challenges  
Helping Your Baby  
Developmental Care  
Caring For Yourself

### What to Expect

### Health Challenges

### Helping Your Baby

### Developmental Care

### Self-Care

<ul style="list-style-type: none"> <li>- Milestones</li> <li>- Immunizations</li> <li>- Hearing Screen</li> <li>- Medications (vit.D, iron, trivisol)</li> </ul>	<ul style="list-style-type: none"> <li>- Feeding complications (using a nipple shield, mastitis, reflux, breastfeeding positions, feeding team)</li> <li>- Physiotherapy (Brachial Plexus, Torticollis, Plagiocephaly)</li> <li>- Occupational therapy</li> <li>- RSV</li> <li>- ROP</li> </ul>	<ul style="list-style-type: none"> <li>- Feeding your baby safely</li> <li>- Car seats</li> <li>- Safe sleep</li> <li>- Involvement: rooming-in and breastfeeding</li> <li>- Refining baby care skills</li> </ul>	<ul style="list-style-type: none"> <li>- Cognitive Development</li> <li>- Growth and Development</li> <li>- Stimulate Your Baby's Learning</li> <li>- Your Child's Development from Birth to 3 Years</li> <li>- Hearing Screen</li> </ul>	<ul style="list-style-type: none"> <li>- Relationships</li> <li>- Physical Care</li> <li>- Baby Blues</li> <li>- Community Connections</li> <li>- Developing Confidence</li> </ul>
		<ul style="list-style-type: none"> <li>- Link to Primary Nurses, Involvement</li> </ul>	<ul style="list-style-type: none"> <li>Link to Communicating with your baby, Becoming involved in your baby's care, Baby Talk</li> </ul>	<ul style="list-style-type: none"> <li>Links to Coping with stress, reflection, support, and bonding</li> </ul>

## Discharge

What to Expect  
Health Challenges  
Helping Your Baby  
Developmental Care  
Caring For Yourself

### What to Expect

### Health Challenges

### Helping Your Baby

### Developmental Care

### Self-Care

<ul style="list-style-type: none"> <li>- When will my baby be discharged</li> <li>- Requirements for discharge (car seat challenge, ABD free, back to sleep)</li> </ul>	<ul style="list-style-type: none"> <li>- Feeding Plans/Schedules</li> <li>- Caring for your baby at home</li> <li>- Prescriptions</li> </ul>	<ul style="list-style-type: none"> <li>- Shaken baby syndrome (Purple Crying)</li> <li>- Breastfeeding (signs your baby is getting enough)</li> <li>- Formula feeding (Storing and Preparing/Choosing Bottles and Nipples)</li> <li>- Follow-up appointments</li> </ul>	<ul style="list-style-type: none"> <li>- Follow up programs (IDP, CDC, neonatal follow-up referrals)</li> <li>- Public Health</li> </ul>	<ul style="list-style-type: none"> <li>- Community Resources</li> <li>- Best Beginnings</li> </ul>
	<ul style="list-style-type: none"> <li>- Link to biliary atresia, RSP, ROP</li> </ul>	Ensure links to <ul style="list-style-type: none"> <li>- Growing and Developing: Safe sleep</li> <li>- Baby care activities</li> </ul>		<ul style="list-style-type: none"> <li>- Link to support, connections, relationships, baby blues</li> </ul>

## At Home

What to Expect  
Health Challenges  
Helping Your Baby  
Developmental Care  
Caring For Yourself

### What to Expect

### Health Challenges

### Helping Your Baby

### Developmental Care

### Self-Care

- Routine Checkups	- Community/ Web resources - When to seek medical advice	- Formula feeding your baby: birth to 6 months - Breastfeeding: Donating your milk	- Tummy Time - Starting solid foods for premature babies - Your Child and Play - Your baby at 2,4,6 months	- First days at home - Time for yourself at home - Socialization: Parent Teas
Link to Milestones, Immunizations	Ensure links to: RSV Formula feeding/feeding complications	- Link to topics in Discharge section - Link to car seats - Link to airway management	Ensure links to - Growing and Developing: Cognitive Development - Growth and Development - Stimulate Your Baby's Learning - Your Child's Development Birth to3	Ensure to link: Growing and Developing - Link to support, connections, relationships, baby blues

## Appendix C

### Prenatal Stage Webpages

#### Legend:

Underline and turquoise signifies a link (Actual link is represented below but this won't be seen on actual webpage as families will simply be alerted to a link when the words on the website are highlighted.)

On the **first NICU Best Beginnings page** the user will be able to click on six different stages of the NICU journey: [Prenatal](#), [Admission](#), [Early Days](#), [Growing and Developing](#), [Discharge](#), and [At Home](#)

For the following pages within this document:

Page C143: the content that will display when clicking on '[Prenatal](#)'

Page C144-148: the content that will display when clicking on '[What to expect](#)'

Page C149-150: the content that will display when clicking on '[Health Challenges](#)'

Page C151: the content that will display when clicking on '[Helping Your Baby](#)'

Page C153-154: the content that will display when clicking on '[Developmental Care](#)'

Page C155: the content that will display when clicking on '[Self-Care](#)'

## Prenatal

- [What to Expect](#)  
Get to know the NICU, video tours, NICU health care team, and specific information for all visitors.
- [Health Challenges](#)  
Learn why a baby needs NICU care.
- [Helping Your Baby](#)  
Important decisions about feeding your baby in the NICU and expressing breast milk.
- [Developmental Care](#)  
Learn about the importance of developmental care in the NICU
- [Self -Care](#)  
Coping while your baby is in the NICU. Preparing your body for pregnancy, and safety tips for pregnant women.

## Prenatal

### What to expect

The NICU can be overwhelming. Learning more about the NICU may help you feel more comfortable. Here are a few things to know before you go:

### Hand washing

Keeping your hands clean is the most important thing to do before entering the NICU. Cleaning your hands is the best way to prevent infections. Some infections can threaten your baby's life.

#### When to clean your hands:

- Before you enter the NICU
- Before you touch your baby
- After touching an object, like your cell phone or surfaces, like a table or chair
- After you touch your baby
- Before you leave the NICU

#### There are two ways to clean your hands

- [Alcohol based hand rub](#) (ABHR)  
Use after coughing, blowing your nose, or touching an object like your cell phone.  
<http://www.fraserhealth.ca/media/Clean%20your%20hands%20using%20ABHR.pdf>
- [Soap and water](#)  
Use when you enter the NICU, when your hands are visibly dirty, after using the washroom, and after diaper changes.  
<http://www.fraserhealth.ca/media/Clean-your-hands-using-soap-and-water.pdf>

It's OK to ask health care providers, visitors and family members to wash their hands. It's important that everyone works together to protect the babies in the NICU. Teach your visitors the importance of hand washing. It's OK to say...

"Please clean your hands before touching my baby?"

To learn more about [cleaning your hands to protect your baby](#)

<http://www.healthlinkbc.ca/healthfiles/hfile85.stm>

(English) <https://patienteduc.fraserhealth.ca/file/14553.pdf>

(Korean) <https://patienteduc.fraserhealth.ca/file/14851.pdf>

(Punjabi) <https://patienteduc.fraserhealth.ca/file/14852.pdf>

(Chinese) <https://patienteduc.fraserhealth.ca/file/14853.pdf>

(Simplified Chinese) <https://patienteduc.fraserhealth.ca/file/14854.pdf>

## Health screening forms

Another way we protect NICU babies from infections is by asking everyone to complete a health screening form before they come into the NICU. Parents, family members (including siblings), and friends will be asked to complete these forms once a day. A member of the NICU health care team will give you a form to fill in when you come into the NICU and review the completed form before you go into the NICU. Please ask a member of the NICU health care team

## Visitor lists

When you are not present family and friends can visit your baby if you complete a visitors list. You will be asked to complete this list if your baby is brought to the NICU. The NICU health care team is here to protect your baby and may ask for identification.

## NICU hospital tours

[View a tour of the NICU at our hospitals.](http://www.fraserhealth.ca/your-health/best-beginnings/labour-and-birth/your-hospital-stay/your-delivery-hospital/at-your-hospital)

<http://www.fraserhealth.ca/your-health/best-beginnings/labour-and-birth/your-hospital-stay/your-delivery-hospital/at-your-hospital>

## Getting to know the NICU

Your family is at the heart of every decision: we welcome you as partners in your baby's care, and we value your needs, preferences, and cultural beliefs. We welcome you to stay and participate in the care of your baby as much as possible.

### Specialized equipment

There is a lot of special equipment in the NICU which can be scary and overwhelming. This equipment is used to help your baby. Learning more about what you may see and hear may help to make you feel more comfortable.

- Your baby may be in an **incubator** (isolette), **overhead warmer**, **cot**, or **crib**.
- **Monitor wires** may be placed on your baby's chest and stomach, like small stickers. This lets the nurse monitor your baby's heart rate and breathing. The monitor may alarm at times but this does not always mean that your baby needs help. Ask your nurse about the monitor and how it is

used. The NICU health care team is skilled in responding to the alarms and will be able to tell you why the monitor is alarming.

- Your baby will also have a **pulse oximeter** (oxygen saturation monitor) wrapped around their foot or hand to monitor oxygen levels.
- Some babies need machines to help them breathe. This may be a **ventilator** or **CPAP** (continuous positive airway pressure) machine.
  - With a ventilator, your baby will have a tube in their throat to help them breathe and may give oxygen.
  - With a CPAP machine, your baby will have a mask or prongs on their nose. The machine will push air into their lungs and may give oxygen.
- Your baby may need to have an **intravenous** (IV) to deliver fluid, nutrition, and medications through a vein. An IV can be placed in your baby's foot, hand, head, or umbilical cord.
- Another type of tube used to give babies nutrition is a **nasogastric tube** (NG) or **orogastric tube** (OG). A NG/OG is inserted into the nose or mouth and goes all the way down to the stomach. Milk can be given to your baby through the NG/OG until your baby is able to eat on their own.
- **Phototherapy** lights may be used if your baby has [jaundice](#).  
<http://www.fraserhealth.ca/your-health/best-beginnings/life-with-your-baby/is-this-normal-/is-this-normal->

Learn more about [getting to know the NICU](#).

<http://www.healthlinkbc.ca/healthtopics/content.asp?hwid+tn5684#tn5697>

### **NICU routines**

There can be a lot of activity in the NICU but knowing some of the routines might help you become more familiar with what is going on.

Most NICU nurses work 12-hour shifts. At shift change nurses give each other important details about your baby. Your nurse will know when your baby will have tests, feeds, diaper changes, baths, and temperatures. Talk to your baby's nurse about their routines so that you can get involved.

The entire NICU health care team will meet or talk daily about your baby and any changes to your baby's care. You are welcome to be present and participate during these discussions. In some NICUs these discussions are called rounds.

### **Your NICU health care team**



The NICU health care team work together and create what is called a multi-disciplinary team. The team works closely together to make sure your baby receives the best care. The team may include:

- **NICU Unit Clerk:** A unit clerk welcomes families and visitors to the unit while also supporting the NICU health care team by processing physician orders, maintaining patient charts, coordinating follow-up appointments, and answering phones.
- **NICU Nurse:** A Registered Nurse (RN) with specialized training and education to care for babies in the NICU.
- **Patient Care Coordinator (PCC):** Also known as the charge nurse. PCCs run the day-to-day activities of the NICU and coordinate the care of the unit. If you have any questions or concerns you can talk to your baby's nurse or the PCC.
- **Pediatrician or Clinical Associate:** A doctor with specialized education to treat babies and children of all ages.
- **Neonatologist:** A pediatrician with specialized education to care for babies who are sick or premature.
- **Resident:** This is a doctor who is training for a specialty.
- **Respiratory Therapist (RT):** An RT has specialized training and education on the use of the breathing equipment. They work closely with the Neonatologist and NICU Nurse to help your baby with any breathing problems.
- **Lactation Consultant (LC):** A LC has specialty training and education in breastfeeding, milk production, and expressing breast milk.
- **Social Worker:** A social worker will see you within the first few days of your baby's NICU stay in order to provide you with emotional support, orient you to the resources and routines of the NICU, and assist in linking you with appropriate community resources.
- **Neonatal Therapists :** Neonatal Therapists are Occupational Therapists (OT), Speech-Language Pathologists (SLP), and Physiotherapists (PT) with specialized training and education in infant growth and development. These therapists may be involved with helping your baby in the areas of feeding, movement, development, communication and preparing to go home.
- **Registered Dietitian:** A dietitian has specialized education and training in infant nutrition. They focus on making sure your baby is getting the best nutrients to grow and develop.
- **Pharmacist:** The pharmacist has specialized training and education about the medication your baby is getting. They can teach you about these medications as well as the medications you are taking.
- **Manager:** The manager is responsible for the unit and supervises the staff.
- **Clinical Nurse Educator (CNE):** The CNE is responsible for teaching and supporting the NICU nurses.

- **Access Flow Coordinator:** The coordinator helps to make sure babies are in the right NICU at the right time, throughout their NICU journey.
- **Discharge Planning Nurse:** The discharge planning nurse may support your family by organizing resources you will need to care for your baby to ensure a seamless transition to home.
- **Clinical Nurse Specialist (CNS):** A CNS is a registered nurse with specialized education who supports the team and leads the development of policies to that make sure all NICUs deliver excellent care.

## Prenatal Health Challenges

There are many reasons why babies are in the NICU and it is usually unexpected. Here are some reasons why babies need NICU care:

- Born early or [premature birth](#):  
When a baby is born 3 or more weeks before your due date.  
<http://www.healthlinkbc.ca/healthtopics/content.asp?hwid=tn5684#tn5687>
- Born very early or [extremely premature](#):  
When a baby is born between 22 and 26 weeks gestation (3-4 months early).  
<http://www.healthlinkbc.ca/healthtopics/content.asp?hwid=zx3825>
- Small or low birthweight also known as [intrauterine growth restriction \(IUGR\)](#): When a baby is born smaller than they should be for their age.  
<http://www.mountsinai.on.ca/care/placenta-clinic/complications/placentalinsufficiency/iugr>  
[http://kidshealth.org/PageManager.jsp?lic=304&dn=Willis\\_KnightonHealth\\_System&article\\_set=84038&cat\\_id=139](http://kidshealth.org/PageManager.jsp?lic=304&dn=Willis_KnightonHealth_System&article_set=84038&cat_id=139)
- [Multiple pregnancy](#) :  
When you are pregnant with more than one baby.  
<http://www.healthlinkbc.ca/healthtopics/content.asp?hwid=hw236272>
- Infection or [sepsis](#):  
When the health care team believe that there is an infection such as [Group B Strep](#) in your baby's blood.  
<http://www.healthlinkbc.ca/healthtopics/content.asp?hwid=zp3014spec>  
<http://www.nicu-pet.com/wp-content/uploads/2014/11/s-en.pdf>  
<http://sogc.org/publications/group-b-streptococcus-gbs-infection-in-pregnancy/>
- [Congenital heart defects](#):  
Heart problems develop before your baby is born. Some heart problems are discovered before birth and some are not found until after birth. There are many types of heart defects. Learn about the different [types of congenital heart defects](#)  
<http://www.healthlinkbc.ca/healthtopics/content.asp?hwid=hw253542>  
<http://www.healthlinkbc.ca/healthtopics/content.asp?hwid=tx4010>
- Maternal complications such as [pre-eclampsia \(PIH\)](#), [maternal substance use](#), or [diabetes during pregnancy](#) :  
Some women have pregnancy complications that result in a baby needing NICU care.  
<http://www.healthlinkbc.ca/healthtopics/content.asp?hwid=hw2834>

<http://www.aboutkidshealth.ca/En/ResourceCentres/PregnancyBabies/Pregnancy/ProblemswiththeBaby/Pages/Neonatal-Abstinence-Syndrome.aspx>  
<http://www.aboutkidshealth.ca/En/ResourceCentres/PregnancyBabies/Pregnancy/MaternalConditions/Pregnancy/Pages/Diabetes-and-Pregnancy.aspx>

- Birth defects associated with the intestines such as [diaphragmatic hernia](#), [gastroschisis](#), [omphalocele](#), defects associated with the face such as [cleft lip/palate](#), defects associated with the spine such as [spina bifida](#), and defects associated with [genes](#) such as [down syndrome](#) or [trisomy 18](#): There are [tests](#) that can be done during pregnancy to look for some birth defects but some defects are found at birth.

<http://www.stanfordchildrens.org/en/topic/default?id=diaphragmatic-hernia-90-P02357>  
<http://www.healthlinkbc.ca/healthtopics/content.asp?hwid=nord923>  
<http://www.stanfordchildrens.org/en/topic/default?id=omphalocele-90-P02012>  
<http://www.healthlinkbc.ca/healthtopics/content.asp?hwid=aa112054>  
<http://www.healthlinkbc.ca/healthtopics/content.asp?hwid=hw169956>  
<http://www.healthlinkbc.ca/healthtopics/content.asp?hwid=tv7695#tv7696>  
<http://www.healthlinkbc.ca/healthtopics/content.asp?hwid=hw167776>  
<http://www.healthlinkbc.ca/healthtopics/content.asp?hwid=nord217>  
<http://www.healthlinkbc.ca/healthtopics/content.asp?hwid=uf6260>

## Prenatal

### Helping Your Baby

You are the voice for your baby. Babies in the NICU need the love and attention that only families can give. Your participation in your baby's care is very important.

Things to do before your baby is born:

- Have a discussion with your health care provider about how you plan to feed your baby. Your health care providers will listen to your questions and answer them accurately and thoughtfully. Learn more about [feeding your baby in the NICU](#) and [breastfeeding](#).

(English) <https://patienteduc.fraserhealth.ca/search/results/109082>

(Punjabi) <https://patienteduc.fraserhealth.ca/file/112110.pdf>

(Vietnamese) <https://patienteduc.fraserhealth.ca/file/112111.pdf>

(Chinese Simplified) <https://patienteduc.fraserhealth.ca/file/112112.pdf>

(Chinese) <https://patienteduc.fraserhealth.ca/file/120797.pdf>

(Korean) <https://patienteduc.fraserhealth.ca/file/112113.pdf>

(Persian) <https://patienteduc.fraserhealth.ca/file/112114.pdf>

(Filipino) <https://patienteduc.fraserhealth.ca/file/112115.pdf>

(Hindi) <https://patienteduc.fraserhealth.ca/file/120798.pdf>

<http://www.fraserhealth.ca/your-health/best-beginnings/breastfeeding/>

- Learn more about [what to expect in the NICU](#).

[Link to BB Prenatal/What to expect page](#)

- Learn more about [developmental care](#).

[Link to BB Prenatal/Developmental care page](#)

Things you can do after your baby is born are:

- Ask your NICU nurse to help you with [Skin-to-skin cuddles](#).
- Ask the NICU health care team lots of questions so that you understand why your baby is in the NICU and what care your baby is getting in the NICU. Learn more about [communicating with the NICU team](#) and members of the [NICU health care team](#).

[Link to BB Admission/Caring for yourself page](#)

<http://www.nicu-pet.com/wp-content/uploads/2014/11/com-en.pdf>

[Link to BB Prenatal/ What to expect page](#)

- If your baby is premature, ask NICU nurses or the NICU developmental therapists (OT, SLP, PT) about your baby's development and what you

can do. Learn more about your [premature baby](#), your [extremely premature baby](#), and [signs of overstimulation](#).

<http://www.healthlinkbc.ca/healthtopics/content.asp?hwid=tn5684#tn8415>

<http://www.healthlinkbc.ca/healthtopics/content.asp?hwid=zx3825>

<http://www.healthlinkbc.ca/healthtopics/content.asp?hwid=tn7258>

- Ask your NICU nurse to help you learn to take your baby's temperature and change your baby's diaper. Learn more about [baby care](#) in [baby's best chance](#).

<https://www.healthyfamiliesbc.ca/home/articles/topic/bathing-diapering-skin-care>

<https://www.healthyfamiliesbc.ca/about-us/additional-resources#BBC>

## Resources

### [Breastfeeding](#)

<http://www.healthlinkbc.ca/healthfiles/hfile70.stm>

### [Breastfeeding Classes for Pregnant Moms](#)

<https://patienteduc.fraserhealth.ca/file/20402.pdf>

### [Expressing your breastmilk](#)

<https://patienteduc.fraserhealth.ca/file/37673.pdf>

## Prenatal Developmental Care

Developmental care helps babies and their families cope with life [in the NICU](#). As family you are a very important part of your baby's development. After birth your baby's brain is growing a lot and growing fast. The NICU team will teach you how you can best help your baby grow and develop.

Developmental care will decrease your baby's stress and conserve your baby's energy. For example, [skin-to-skin care](#), ([NICU specific S2S pamphlet](#)) also known as Kangaroo Care, is an important way you can help support your baby's development and keep your baby calm. To learn more about doing skin to skin with your baby please ask a NICU nurse or neonatal therapist.

Even very tiny babies have ways to communicate with you about how they are feeling and what they need. Understanding your baby's behaviour helps you interact with your baby in ways that help them grow and develop. For example, you will learn when your baby is stressed or relaxed. For times when your baby is stressed you will learn how to calm and support your baby. For times when your baby is relaxed you will learn how you can play and interact with your baby.

You will also notice that the NICU staff support developmental care too. For example, NICU staff place covers over your baby's incubator, talk quietly around your baby, place your baby in a calming position when possible, and try to plan your baby's care activities to decrease your baby's stress and help your baby have longer periods of sleep.

Learn more about [developmental care](#)

<http://www.nicu-pet.com/wp-content/uploads/2015/02/Developmental-Care.pdf>

<http://www.aboutkidshealth.ca/En/HealthAZ/DevelopmentalStages/MaternalandNewborn01month/Pages/Developmental-Care-in-the-NICU.aspx>

## Resources

### [Newborn growth and development](#)

<http://www.healthlinkbc.ca/healthtopics/content.asp?hwid=hw42229>

<http://www.healthlinkbc.ca/healthtopics/content.asp?hwid=hw251065#te4698>

<http://www.healthlinkbc.ca/healthfiles/hfile92b.stm>

### [Newborn development](#)

<https://www.healthyfamiliesbc.ca/home/articles/topic/baby-development>

### [Your baby's development in the NICU](#)

**ADD from FHA catalogue**

Communication from birth to 5 years of age

<https://patienteduc.fraserhealth.ca/file/86557.pdf>



## Prenatal Self-Care

It can be a challenge to take care of yourself during pregnancy. Making sure you have a [healthy diet](#), [exercise](#), rest, [dental care](#), prenatal care with a [health care professional](#), and [up-to-date immunizations](#) are all great ways to [care for yourself](#) and your baby.

<https://patienteduc.fraserhealth.ca/file/932.pdf>

<https://patienteduc.fraserhealth.ca/file/933.pdf>

<http://www.fraserhealth.ca/your-health/best-beginnings/pregnancy/healthy-eating/healthy-eating>

<https://patienteduc.fraserhealth.ca/file/20909.pdf>

<http://www.fraserhealth.ca/your-health/best-beginnings/pregnancy/dental-care/dental-care>

<http://www.fraserhealth.ca/your-health/best-beginnings/pregnancy/choosing-a-health-care-professional/choosing-a-healthcare-professional>

<http://www.fraserhealth.ca/your-health/best-beginnings/prepare-for-pregnancy/prepare-your-body/health-care/pre-pregnancy-health-care>

<http://www.fraserhealth.ca/your-health/best-beginnings/prepare-for-pregnancy/prepare-your-body/health-care/pre-pregnancy-health-care>

You may notice your ability to manage stress is improved when you prioritize taking care of yourself. Your growing baby also benefits when you and healthy and well. It is also important to know about the [safety tips for pregnant women](#).

<http://www.fraserhealth.ca/your-health/best-beginnings/pregnancy/health-and-safety/health-and-safety>

There is a lot to learn about [pregnancy](#) so don't try to read everything at once. You can read small amounts during each stage of pregnancy so you don't get overwhelmed.

<http://www.healthlinkbc.ca/healthtopics/content.asp?hwid=hw197814>

If you know your baby will be admitted to the NICU then it may be helpful for you to learn more about [what to expect in the NICU](#).

[Link to BB Prenatal/What to expect](#)

## Resources

### [Parenting in the NICU](#)

<http://nicuparenting.org/Parents.html>

### [Self-Care](#)

<http://handtohold.org/resources/helpful-articles/the-four-areas-of-self-care/>

Community Resources include [Options Community Services](#), [Surrey Women's Centre](#), [Maxine Wright Community Health Centre](#), and [Klahoweya](#)

<http://www.options.bc.ca/>

<http://www.surreywomenscentre.ca/>

<http://www.atira.bc.ca/maxxine-wright-community-health-centre>

<http://klahoweya.com/index.php/programs-services/for-families/expectant-parent-support-group/>

## Appendix D

### Sample Pamphlet



Easy online access to health information and resources

 [bestbeginnings.fraserhealth.ca](http://bestbeginnings.fraserhealth.ca)

<p><b>Prepare for Pregnancy</b></p> <ul style="list-style-type: none"><li>Understand Fertility</li><li>Prepare Your Body</li><li>Plan Your Finances</li><li>Manage Relationships</li></ul> <p><b>Pregnancy</b></p> <ul style="list-style-type: none"><li>Prenatal Registration</li><li>Prenatal Classes</li><li>Breastfeeding Classes</li><li>Tests, Scans and Checks</li><li>Healthy Eating and Foods to Avoid</li></ul> <p><b>Labour and Birth</b></p> <ul style="list-style-type: none"><li>Stages of Labour</li><li>When to Go to the Hospital</li><li>Preparing for the Unexpected</li><li>Your Hospital Stay</li><li>Your Body After Birth</li></ul> <p><b>Breastfeeding</b></p> <ul style="list-style-type: none"><li>Getting Started</li><li>Do I Have Enough Milk?</li><li>Sore Nipples and Breasts</li></ul>	<p><b>Your Baby (0-6mo)</b></p> <ul style="list-style-type: none"><li>Coping with Crying</li><li>Safe Sleep</li><li>Is this Normal?</li><li>Nutrition and Vitamin D</li><li>Growth and Development</li><li>Immunizations and Shots</li></ul> <p><b>Your Toddler (6-24mo)</b></p> <ul style="list-style-type: none"><li>Healthy Eating</li><li>Introducing Solids</li><li>Sleep Habits</li><li>Teething and Tooth Care</li><li>Growth and Development</li><li>Positive Parenting</li></ul> <p><b>For Dads</b></p> <ul style="list-style-type: none"><li>Taking Care of Your Baby</li><li>Dad's Role in Breastfeeding</li><li>Sex After Pregnancy</li></ul> <p><b>Depression and Anxiety</b></p> <ul style="list-style-type: none"><li>Signs and Symptoms</li><li>Finding Supports</li></ul>
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## Appendix E

### Snapshots of Neonatal Checkpoint

**FHpulse**

HOME > CLINICAL RESOURCES > NEONATAL CARE

**VIEW MAIN CATEGORIES ▾**

**Clinical Resources**  
+ 48/6

- Automated Medication Distribution System (AMDS/PYXIS)
- Care Sensitive Adverse Events (CSAE)
- Clinical Capacity Optimization
- Clinical Policy Office
- Clinical Standardization
- CPN eDoc
- Diversity & Language Services

## Neonatal Checkpoint

YOUR COMPREHENSIVE NICU CLINICAL RESOURCE!!

### Neonatal Clinical Resources

- CDSTs (Policies)**
- Mosby's Skills (Procedures)**
- Parent Education Resources**
- Neonatal Lab Manual**
- OE Resource (excluding Lab)**
- Phototherapy Graphs**
- Hypoglycemia Resources**
- CPS**
- ACoRN**
- ARH**
- BH**
- RCH**
- SMH**

**FHpulse**

HOME > CLINICAL RESOURCES > NEONATAL CARE

**VIEW MAIN CATEGORIES ▾**

**Clinical Resources**  
+ 48/6

- Automated Medication Distribution System (AMDS/PYXIS)
- Care Sensitive Adverse Events (CSAE)
- Clinical Capacity Optimization
- Clinical Policy Office
- Clinical Standardization
- CPN eDoc
- Diversity & Language Services
- eHealth
- eHealth Viewer
- Ethics Services

**Actions ▾** View: **All Items**

Edit	Title	Languages
	Breast Feeding	English, Chinese, French, Punjabi, Spanish, Vietnamese
	Car Seat - Rear Facing	English
	Car Seat Safety - Parent D/C Handout	English
	Car Seat Safety - Tiny Babies	English
	Discharge Teaching Resource List - NICU	English
	Donor Milk	English
	Expressing Your Breast Milk: Getting Started when Your Baby is in the Hospital	English
	Expression Record	English
	Feeding Your Baby (0-6 months)	English
	Feeding your baby in the NICU: Information to help with decisions	English, Hindi, Korean, Persian, Punjabi, Vietnamese, Chinese Simplified, Chinese Traditional, Filipino
	First Day Home - D/C Pamphlet	English, Arabic, Chinese-simplified, Farsi, Korean, Punjabi
	Formula Feeding Your Baby: Getting Started	English, Chinese, French, Punjabi, Spanish, Vietnamese
	Formula Feeding Your Baby: Safely Preparing and Storing Formula	English, Chinese, French, Punjabi, Spanish, Vietnamese

## **Appendix F**

### **Next Steps**

- Obtain feedback for the Prenatal template page from the entire FHA NICU team and NICU families
- Consider feedback and revise Prenatal template page accordingly
- Complete and revise all the webpages
- Obtain feedback for all the webpages from entire FHA NICU team and NICU families.
- Consider feedback and revise webpages accordingly
- Create one page pamphlet that HCPs can use as a tool to direct NICU families to website (this pamphlet will indicate where to find information on specific topics).
- Add all NICU education to Neonatal Checkpoint (to improve HCPs' access to education)

### **Timeline for Next Steps of the FHA Online NICU Family Education**

<b>Method</b>	<b>Duration</b>
- Obtain feedback for the Prenatal webpages	1 month
- Review feedback and revise	2 weeks
- Complete and revise all the webpages	5 months (1 stage per month)
- Obtain feedback for the rest of the webpages	1 month: Complete 1 stage at a time after each stage is completed.
- Review feedback and revise	2 weeks
- Create on page pamphlet	2 months
- Add all NICU education to Neonatal Checkpoint	1 month

## **Appendix G**

### **Implementation and Evaluation Plan**

- 1) Describe the program: Develop a structured, comprehensive, and graphic description of the project (McKenzie et al., 2013; Taylor-Powell, Jones, & Henert, 2003).
  - a. Create logic model with vision statement (see Appendix H)
  - b. Develop vision statement for revised website that concisely and comprehensively describes why revisions to the website were made and the revised website's goals

Application of the evaluation standards ensure the vision statement and logic model are concise, inclusive, and realistic (U.S. HHS CDC, 2011).

- 2) Engage key stakeholders and target population: Identify the individuals that are involved throughout the program planning process, participants of the program, or anyone who applies the evaluation results (U.S. HHS CDC, 2011).
  - a. Identify key stakeholders that will help to ensure the guide is reliable, implemented, endorsed, and supported: NICU HCPs, NICU families, and perinatal HCPs.
  - b. Identify target population: FHA NICU families but the guide will also help augment NICU HCPs and perinatal HCPs face to face teaching.
  - c. Prepare key stakeholders for Website launch: Prepare an engaging presentation that will increase awareness of revised website and specify its value. Use the vision statement and logic model during presentations.
    - Present at the clinical practice committee, leadership meetings, and professional practice council.

- Also create posters and send emails that concisely introduce the guide to key stakeholders.
- d. Select date for launch and create enthusiasm and momentum among the key stakeholders. This can be done simultaneously with previous step.
- e. Notify FHA NICU families of revised website: Do this by encouraging frontline staff to promote the website during their interactions with NICU families. Also prepare posters and distribute pamphlet (Use the pamphlet created for HCPs that indicates website address and what and where specific topics are located).

Application of the evaluation standards help to identify which stakeholders have the availability and expertise to participate as well as who will benefit from the results (U.S. HHS CDC, 2011).

- 3) Focus the evaluation design: Plan to conduct a summative evaluation which aims to evaluate the effectiveness of the program (McKenzie et al., 2013). Specific focus on if NICU families are accessing the website and conduct informal consultations with NICU HCPs and NICU families.
  - a. Evaluate website traffic: In consultation with the communications department obtain statistics that compares website traffic before and after implementation of revised website.
  - b. Conduct informal consultations:
    - NICU HCPs: Focus discussions on families informational needs and frequently asked questions (similar to needs assessment)

- NICU families: Focus discussion on accessibility, consistency, and content of education.

Application of the evaluation standards facilitates identification of the purpose of the evaluation and who will benefit from the results of the evaluation while also ensuring the evaluation is realistic, suitable, and relevant (U.S. HHS CDC, 2011).

- 4) Gather Credible Evidence: Ensure the evaluation is organized and completed.
  - a. Select someone to lead and manage the evaluation. Management will include overseeing the expenses, consideration of ethics approval, and creating the timeline. This may include a need to seek ethics approval by the FHA.

Application of the evaluation standards guides the leader to include key stakeholders throughout the evaluation process while also verifying that the evaluation is conducted appropriately (U.S. HHS CDC, 2011). There may be the need to seek advice from evaluation experts such as an epidemiologist or clinical nurse specialist.

- 5) Justify Conclusions: Identify data that validates the project while also ensuring that the stakeholders can appreciate the data (U.S. HHS CDC, 2011). For the purposes of this program it will be important reflection to reflect on the principles of FCC when interpreting the data.

- a. Analyze data and relate the results to the program's values.

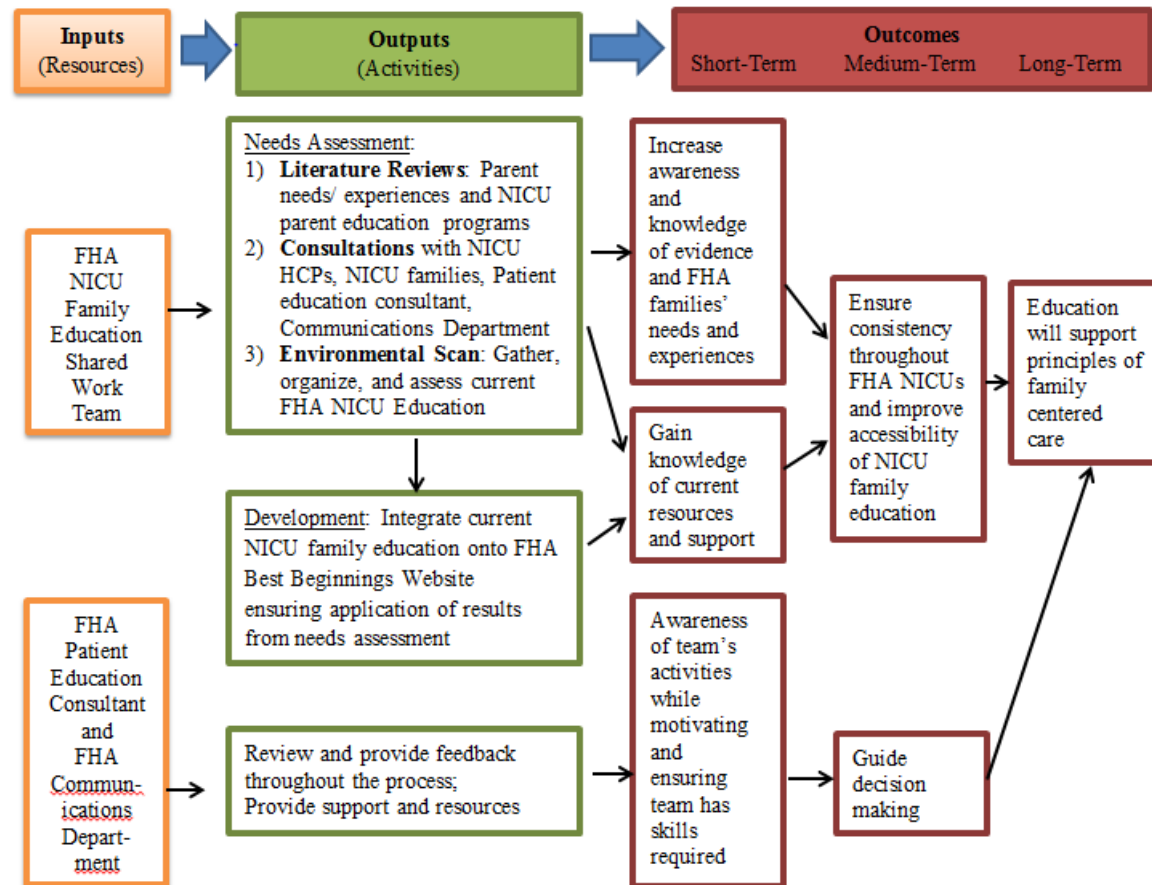
Application of the evaluation standards ensures data is analyzed appropriately and that consideration of all possible interpretations has occurred while also verifying that the description of the results is understandable (U.S. HHS CDC, 2011).

- 6) Reflect, Recommend, Seek Feedback, and Disseminate: Identify how the evaluation results will be used, consider the feedback from all stakeholders, and communicate the results (U.S. HHS CDC, 2011).
- a. Reflect upon the steps involved with developing, implementing, and evaluating the program. Aim to ensure that all stakeholders feel appreciated and valued.
  - b. Consider all feedback and make changes to website based on feedback. It will be important, however, not to be too reactive to feedback obtained. Ensure to include rationale as to the outcomes of the feedback (induced change or not).
  - c. Disseminate results of evaluations with key stakeholders through presentations at meetings, e-mail, and poster presentations. The main goal of dissemination will be to facilitate ongoing awareness of this resource as well as foster key stakeholders' commitment and enthusiasm for this resource.

Application of the evaluation standards will facilitate the development of an accessible, impartial, organized, concise, and comprehensive report (U.S. HHS CDC, 2011)



## Appendix H Logic Model and Vision Statement



**Vision Statement:** FHA NICUs value FCC but there is limited evidence incorporating FCC into practice. Providing families with education supports FCC but, current family education in FHA NICUs is deemed to be inaccessible, inconsistent, and disorganized. This project aims to support the principles of FCC by reflecting upon the needs of families throughout their NICU journey in order to create a centralized, engaging, organized, and family-directed FHA online NICU family education guide.